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Young women's experiences of health-related psychosocial difficulties

Treasa McCarthy

This thesis is submitted in partial fulfillment of the requirements
for the degree of Doctorate in Clinical Psychology

Coventry University, Faculty of Health and Life Sciences
University of Warwick, Department of Psychology

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List of abbreviations

BPS British Psychological Society

CASP Critical Appraisal and Skills Programme

CINAHL Cumulative Index to Nursing and Allied Health Literature

FP Fertility Preservation

HCPs Healthcare professionals

IPA Interpretative Phenomenological Analysis

IRP Intimate Partner Relationship

NHS National Health Service

NICE National Institute for Health and Care Excellence

PCOS Polycystic Ovary Syndrome

PIS Participant information sheet

PRISMA Preferred Reporting Items for Systematic Reviews and Meta-analysis

QoL Quality of Life

UK United Kingdom

USA United States of America

WwPCOS Women with PCOS

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Declaration

This thesis has not been submitted to any other institution. It has been conducted under the clinical and academic supervision of Dr. Carolyn Gordon (Clinical Psychologist and Academic Tutor, Coventry University) and Dr. Carol Percy (Senior Lecturer in Psychology and Research Supervisor, Coventry University). Apart from the collaborations stated, all of the material presented in this thesis is my own work. It is intended that chapter one will be submitted to *Health Care for Women International Journal*, and chapter two to *Qualitative Health Research*.

Summary

This thesis focuses on young women's experiences of health-related psychosocial difficulties. Fertility-related difficulties are a common and distressing issue for young women following cancer. Chapter one describes a meta-ethnography of qualitative literature that explores how young women experience their fertility following cancer treatment. Two meta-themes are described, which illustrate the multiple losses women experience related to their threatened or lost fertility, and the complex grieving process they engage in to come to terms with these losses. Clinical implications are highlighted.

Polycystic ovary syndrome (PCOS) is a common chronic endocrine condition associated with physical, psychological and sexual difficulties. Chapter two describes the experience of being in intimate partner relationship as a young woman with PCOS. Seven young women were interviewed using an Interpretative Phenomenological Analysis methodology. Two superordinate themes emerged. The study identifies how the women's threatened feminine identities undermined their relationship security and sometimes created a power imbalance between them and their partners. The battles to repair their feminine identities, and how these are experienced in the context of their intimate partner relationships, are then discussed. Difficulties with sexual intimacy are also described. A number of clinical implications are identified.

Chapter three presents a reflective account of the research process, both regarding how the researcher may have influenced the research, and how the research influenced them. A number of areas of reflection are outlined, including the challenge of being a clinician and a researcher and managing being an 'outsider'. The chapter ends by reflecting on the role research can play in reinforcing or challenging social norms.

Overall word count: 19,266 at submission (excluding abstracts, tables, figures and references).

CHAPTER ONE

“Am I still whole?”: a meta-ethnographic review of qualitative studies exploring young women’s experience of their fertility following treatment for cancer.

This chapter was prepared for submission to the *Health Care for Women International Journal* (see Appendix A for author guidelines from this journal).

Word count: 7,860 (excluding abstract, figures, tables and references).

Abstract

Uncertain or lost fertility following cancer is a significant issue for young women. This systematic review aims to synthesise qualitative literature on young women's experience of their fertility following cancer treatment. Meta-ethnography was utilised to synthesise the literature. Five electronic databases that catalogue relevant research were searched, resulting in 11 studies for analysis. The analysis produced two meta-themes and seven sub-themes. Following cancer, women often experience a sense loss in relation to their fertility, as well as related losses in life plans, their femininity identity and relationships. This sense of loss is often compounded by uncertainty regarding their fertility status. Many women experience ambivalence about motherhood, balancing the risks and benefits. While some women describe a prolonged process of grief, others find ways of coming to terms with their losses and accepting their altered fertility. Young women with cancer require ongoing practical and emotional support regarding their fertility from diagnosis into survivorship.

Abstract word count: 152

Keywords: cancer-related infertility; premature menopause; young women; cancer treatment; meta-ethnography.

1.1 Introduction

1.1.1 Overview

Cancer and cancer treatment can cause distressing and debilitating short- and long-term side effects, including compromised or lost fertility for women of childbearing age (Partridge & Ruddy, 2007). The aim of this systematic review is to critically evaluate and synthesise the qualitative literature on young women's experience of their fertility following treatment for cancer.

The key concepts are defined as follows:

- a young woman is defined as any woman aged between 14 and 50 years (Dunn & Steginga, 2000);
- cancer treatment is defined as any form of conventional medical treatment for cancer, including chemotherapy, radiotherapy or surgery (Miller et al., 2016);
- fertility is defined as the ability to conceive children (Vander Borgh & Wyns, 2018).

1.1.2 Review subject and significance

1.1.2.1 Cancer and fertility

Over 2,000 children and young adults are diagnosed with cancer in the UK annually (National Institute for Health and Research Excellent [NICE], 2014) and over 6% of breast cancer diagnoses (the most common cancer in women) occur in women under 40 (Assi et al., 2014; Miller et al., 2016). In England, up to 50% of women diagnosed with breast cancer survive for over ten years and up to 85% of childhood cancer patients are predicted to survive over five years (Office of National Statistics [ONS], 2019). This increase in

long-term cancer survival rates has stimulated a growing interest in factors that impact upon survivors' recovery, quality of life (QoL) and wellbeing.

Indeed, while survival rates improve, cancer treatment often results in significant long-term side effects that can have a significant negative impact on QoL (Siegel et al., 2012). For young women, cancer or cancer treatment can compromise fertility through temporary or permanent damage to the reproductive organs and/or mandatory delayed childbearing (Knobf, 2009; Meirrow & Schenker, 1996). A recent review found that 33% to 73% of young women reported being peri- or post-menopausal following breast cancer treatment (Howard-Anderson et al., 2011). Women's fertility status can remain unknown for some time post-treatment, as determining their status can be challenging, and conception is often discouraged for two to ten years post-treatment (Waimey et al., 2015).

1.1.2.2 The psychosocial impact of cancer-related fertility difficulties

For young women, fertility is a significant issue during and after cancer treatment (Partridge et al., 2004; Canada & Schover, 2012). Reproductive concerns are associated with fertility-related distress and long-term depression (Gorman et al., 2015) and can negatively affect identity, creating a sense of 'biographical disruption' (Ussher & Perz, 2018). Women with breast cancer are also half as likely to become pregnant after treatment compared with women without cancer (Ives et al., 2007), with infertility unlikely to fully account for this difference. Furthermore, the increasing prevalence of delayed childbearing means the number of young women with cancer who wish to conceive is likely to increase (Organisation for Economic Co-operation and Development [OECD], 2018).

Given the importance of fertility to patients, NICE recommends that all young people diagnosed with cancer are assessed for potential fertility problems and informed of preservation options prior to treatment (NICE, 2014). Numerous fertility preservation (FP) options are available for women with cancer. However, conception rates remain modest (De Vos, Smits & Woodruff, 2014). Providing support around fertility may have significant benefits to patients. FP counselling and treatment have been found to improve QoL and lower decisional regret regarding FP in reproductive-aged women (Letourneau et al, 2013).

Despite the above benefits, a significant portion of young women report a lack of information about either the impact of treatment on fertility (Duffy, Allen & Clark, 2005) or information regarding FP (Mancini et al., 2007). United Kingdom (UK) oncologists identified a number of barriers to discussing FP, including lack of time and knowledge, perceived poor success rates, poor patient prognosis, and to a lesser extent, the patient having prior children or being single (Adams, Hill & Watson, 2013).

1.1.3 Evaluation of previous reviews

A number of systematic reviews published in the past ten years have provided a clearer understanding of women's fertility-related issues and concerns after cancer. Sobota & Ozakinci (2011) systematically reviewed twenty-eight quantitative studies, published between 1990 and 2012, exploring the impact of cancer-related fertility issues on young female cancer patients. The review found that women's psychological wellbeing could be negatively impacted by treatment-related infertility, with higher levels of depression and lower QoL reported by women who perceived themselves as infertile. Although little evidence was available, fertility-related interventions appeared to have a beneficial impact on psychological wellbeing, QoL and decisional regret.

Motivations for parenthood could also be influenced by cancer. Two reviews have explored childbearing attitudes, intentions and decisions of cancer survivors. Schmidt et al. (2016) reviewed twenty quantitative and qualitative studies, published between 1990 and 2013, exploring reproductive intentions and parenthood motivations amongst young male and female cancer survivors (Schmidt et al., 2016). Goncalves, Sehovic & Quinn (2011) undertook a similar review of both quantitative and qualitative studies in the same period, but with a focus on young breast cancer survivors. Both reviews identified numerous concerns regarding parenthood, including cancer recurrence and delayed detection, concerns about the child's health, fears of negative repercussions for partners or financial instability. Despite these concerns, a number of incentives were also identified, including focusing on something positive and achieving a sense of normality.

One qualitative meta-synthesis provided an insight into the processes women engage in to cope with cancer-related difficulties, including fertility-related difficulties. Adams et al. (2011) explored the experiences, needs and concerns of young women with breast cancer. This meta-ethnography, which synthesised seventeen qualitative studies published between 1999 and 2009, identified reproduction and fertility-related concerns as one of the key issues experienced, alongside difficulties with sexuality, adjusting to bodily changes and fears for the future. A number of common experiences were identified, particularly feeling 'out of sync' and not following the expected childbearing trajectory. Women engaged in three inter-related processes to manage their diagnosis: 'balancing', 'normalising' and 'changing'. With regards to reproduction, women 'balanced' treatment decisions with fertility preservation, 'normalised' by having children post-treatment or 'changed' when reproductive decisions were influenced by cancer.

While a number of other reviews on related topics have been conducted, they were not systematic in their approach (Halliday & Boughton, 2011; Penrose et al., 2013) or were over ten years old, and thus did not include up-to-date research (Peate et al., 2009).

1.1.4 Rationale and aim

The above reviews provide a comprehensive account of some of the fertility-related difficulties and concerns young women experience, as well as the complexity involved in making decisions about childbearing. Despite these significant contributions, a number of limitations exist. Schmidt et al. (2016) included mixed-gender participants without conducting separate analyses, despite the likelihood of male and female experiences being different. While the other reviews focused solely on women, both Goncalves, Sehovic & Quinn (2011) and Adams et al. (2011) focused solely on women with breast cancer, excluding women with other types of cancer. Although the participants included in Sobota & Ozakinci's review were young women with any type of cancer, qualitative research was excluded. Indeed, a number of relevant, high-quality qualitative studies that were not included in any of the above reviews have been published in recent years. Furthermore, none of the reviews explored how young women treated for cancer experience their fertility. Rather, they focused either on how fertility-related concerns impact upon psychological wellbeing, how young women with cancer make decisions about childbearing and reproduction, and the broader experiences, needs and concerns of young breast cancer patients.

In light of these limitations, the current review will undertake an interpretive meta-synthesis of qualitative research in this field. The aim of the review is to explore the following question: how do young women treated for cancer experience their fertility? Several qualitative studies have explored this topic, with different studies focusing on different aspects of this multi-faceted experience. It is hoped that this meta-synthesis will provide a richer, more nuanced understanding of this experience, so as to inform the care young women with cancer receive.

1.2 Method

1.2.1 Systematic literature search

1.2.1.1 Search process

Ethical approval for undertaking the meta-synthesis was sought from, and provided by, Coventry University Ethics Department (Appendix B). A systematic search was conducted to search for qualitative or mixed methods studies that addressed the review question. Five electronic databases were searched: Medline, Embase, PsycINFO, Web of Science and Cumulative Index to Nursing and Allied Health Literature (CINAHL). These databases were chosen as they spanned the subject disciplines of both medicine (particularly oncology), nursing and psychology. Grey literature was found by searching Proquest and Google Scholar. Reference lists of relevant papers were also checked. Searches were conducted between December and February 2019.

1.2.1.2 Search terms and search strategy

Four key concepts structured the search: young women, experience, cancer and fertility. Search terms, synonyms and methods of truncation were identified for each key concept (Table 1.1). Database thesauruses and MeSH headings were also used to identify relevant terms. Key concepts and synonyms were combined using Boolean operator 'OR'; key concepts were then combined using Boolean operator 'AND'. For examples of database searches, see Appendix C. Key search terms could be located anywhere in the text of the article.

Table 1.1

List of search terms

	Key Concepts	Synonyms	Location
Population	Young Women	Women Females	Title Abstract Keywords Main text
Context	Experience	Lived experience Meaning Impact Response Perception Adjustment Adaptation Distress Coping Psychosocial needs	Title Abstract Keywords Main text
Outcome	Cancer	Oncolog* Chemotherapy Radiotherapy Malignan* Neoplasms Tumours	Title Abstract Keywords Main text
	Fertility	Infertility Reproductive issues Reproductive ability Fertility preservation Premature menopause	Title Abstract Keywords Main text

*1.2.1.3**Inclusion and exclusion criteria*

Original qualitative or mixed methods studies where the research aim was to explore young women's experience of their fertility, fertility-related experiences or changes to their fertility following cancer treatment were included. Research exploring related experiences were excluded, such as the experience of oncofertility or childbearing intentions, where there was no

exploration of the experience of fertility. Quantitative studies and mixed methods studies without a significant qualitative component were excluded.

Studies where participants were women between the ages of 14 and 50 were included, as this age group broadly constitute childbearing age (Dunn & Steginga, 2000). Studies with both men and women or women outside of this age range were excluded. Participants were also required to have undergone treatment for cancer, as the experiences of women newly diagnosed with cancer are likely to differ significantly from those who are undergoing or have completed treatment. Where full texts could be accessed, unpublished academic theses and dissertations were included to counteract publication bias. Studies had to be available in English to enable interpretation by the author. Research published prior to 1990 was not included, given the advances in cancer treatment and fertility preservation since that time. For full details of the inclusion and exclusion criteria, see Table 1.2.

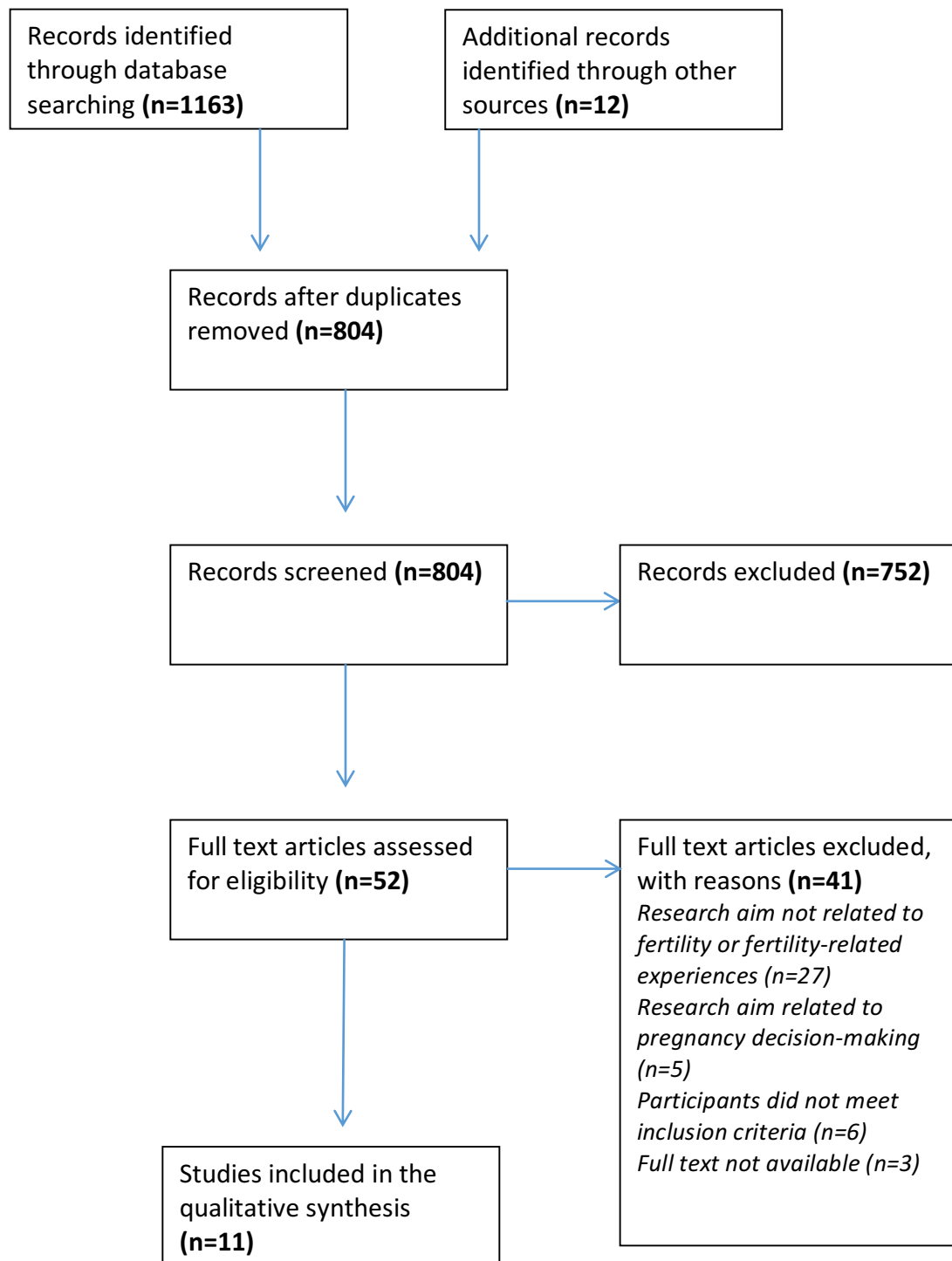
Table 1.2

Inclusion and exclusion criteria

Criteria	Inclusion	Exclusion
Epistemology and Research Design	All qualitative research designs (e.g. IPA, grounded theory, feminist, discourse analysis, thematic analysis) Mixed qualitative and quantitative designs, with a substantial qualitative component (only the qualitative findings included)	Quantitative methodology Non-original articles Mixed methods methodology, where substantial qualitative data could not be extracted
Research Aim	Exploring how women who have been treated for cancer experience their fertility Exploring how women who have been treated for cancer experience fertility-related difficulties related to cancer/cancer-treatment e.g. premature menopause, where the experience of fertility is discussed in the findings.	Exploring women's cancer-related experiences more broadly (not specifically exploring experiences of fertility) Exploring women's experiences of oncofertility during or post-cancer treatment (i.e. fertility preservation or restoration interventions) Exploring women's childbearing intentions or decision-making during or post-cancer treatment Exploring women's experience of parenthood during or post-cancer
Research Findings	Women's experience of their fertility following treatment for cancer	Fertility-related issues or experiences distinct from women's experiences of their fertility (e.g. the pregnancy decision-making process, having children after cancer)
Data Collection Method	Interviews Focus groups Written personal accounts (e.g. diaries, blogs, online forum posts)	Surveys Standardised Measures Observations
Sample	Female participants Aged 14 to 50 years Currently in treatment for cancer, or have been treated for cancer previously Cancer affecting any part of the body All nationalities and ethnicities	Male participants Male and female participants Female participants below age 14 or above age 50 Not yet treated for cancer (e.g. newly diagnosed)
Area	Anywhere in the world	N/A
Language	English	Non-English
Time Period	Published between January 1990 to February 2019	Published prior to January 1990 or after February 2019

Figure 1.1

PRISMA flow diagram (Moher et al, 2009)



1.2.2 Classification of studies

In total, 1163 articles were identified through the electronic database searches, with 12 additional articles found through manual searches. When duplicates were removed, 804 articles remained and the titles and abstracts were screened against the inclusion and exclusion criteria; 752 were removed as not relevant. The remaining 52 articles were read in full, where the full text could be accessed; 11 of these articles met the inclusion criteria and were included in the meta-synthesis. Forty-one papers were removed, the reasons for which are noted on the PRISMA diagram. The entire search process is depicted in Figure 1.

1.2.2.1 *Quality assessment check*

Quality assessment in qualitative research remains a contested practice, despite being well-established in quantitative research. Indeed, some suggest that the epistemological and ontological assumptions underpinning qualitative methodologies mean determining the quality or 'accuracy' of this type of research is both impossible and meaningless, as qualitative research does not seek to make objective or generalisable claims beyond the context and time where the research was carried out (Ring et al., 2011). Furthermore, as with most qualitative meta-syntheses, there is considerable heterogeneity in the qualitative methodologies employed by the studies included in this review. Thus it is debatable as to whether it is possible or useful to compare 'quality' across designs. There is currently little consensus regarding the essential criteria for high-quality qualitative research, with over 100 quality assessment tools available (Ring et al., 2011).

Despite these reservations and challenges, some form of quality appraisal is now employed by most researchers conducting meta-syntheses (Lachal et al., 2017). As such, it was deemed appropriate to use an established quality appraisal tool, while bearing the above limitations in mind. For the purposes of this study, the Critical Appraisal and Skills Programme

(CASP) Checklist was utilised (CASP, 2018), as it addresses the main principles and assumptions underpinning qualitative research (Lachal et al., 2017) and is recommended by the Cochrane Collaborative (Booth et al., 2016). The CASP aims to address three broad issues: what the study's findings are, whether these findings are valid and whether the findings will help locally (CASP, 2018).

The quality of each study was individually assessed against ten criteria. Although the CASP does not produce a quality score, in line with the practices of other researchers (e.g. Lachal et al. 2017; Boeije et al. 2011) a three-point scale was used to weight the assessments (0 = criterion not met; 1 = criterion partially met; 2 = criterion fully met). A cut-off score was not employed, rather the scores were used to categorise the studies into high (scores of 15-20), medium (scores of 10-15) or low (scores 0-10) quality studies. This ensured that all relevant studies could be included in the review, given the concerns about quality assessment of qualitative research cited above. It also provided an indication of the relative weight to put to the findings of each individual study, where the findings from more rigorous studies could be considered as likely to be more robust. All of the studies were rated as high in quality, apart from Thewes et al. (2003), which was classified as 'medium'.

The reliability of the quality assessment process was established by having each study included in the meta-synthesis independently assessed by two researchers. Inter-rater reliability was established using Kappa coefficients (Fleiss & Cohen, 1973). Initial scores ranged from .43 to .9 for individual studies. Where there was significant disagreement in the scores, both researchers discussed the discrepancies and some disagreements were resolved. See Appendix D for the quality scores generated by both researchers. The resulting coefficients ranged from .48 to 1 for individual studies, with an overall Kappa coefficient of .85, which demonstrated good inter-rater reliability.

1.2.2.2 *Characteristics of the literature*

Table 1.3 summarises the key characteristics of the 11 studies included in the meta-synthesis. All of the studies had aims related to young women's experiences of their fertility either during or post-cancer treatment, although the focus was slightly different for all of the studies. All of the studies employed a qualitative methodology. However, a variety of designs were employed: two used a social constructionist approach (one of which used Foucauldian Discourse Analysis), three used a phenomenological approach, one employed a narrative/constructivist approach, while the remaining seven used thematic analysis. Eight of the studies gathered data via one-to-one interviews, either in person or by phone, while two used focus groups and one analysed blog posts. One of the studies employed a longitudinal design and interviewed participants at three time points, while all of the others interviewed participants or analysed blog posts at one time-point.

Seven of the studies recruited by advertising in support groups, charities or online forums, two studies advertised in both the community and hospital clinics and one study recruited solely through an oncology clinic. Data from 140 participants in total contributed to the meta-synthesis, with sample sizes ranging from 4 to 24 (participants from the Halliday, Boughton & Kerridge studies were only counted once, as these studies appeared to draw upon data from the same interviews). All of the participants were aged between 16 and 45. Participants had experienced a number of different types of cancer, with four studies focusing on breast cancer patients, three including haematological cancer patients and four including patients with various types of cancer.

Six of the studies were conducted in Australia, three in the United States of America (USA), two in the UK and one in Canada. Two of the included studies were unpublished dissertations, while all of the other studies were in published journals, having undergone peer review.

Table 1.3

Characteristics of the reviewed studies

Authors, date and geographical location	Quality Rating and Kappa Score	Research Aim(s)	Participants (sampling, inclusion and exclusion criteria)	Design and Method (recruitment procedure, data collection, data analysis)	Key Findings
Connell, Patterson & Newman (2006) Australia	Quality Rating: 17 (high) Kappa Score: .74	<i>To explore the issues and concerns of young women with a focus on experiences of fertility and infertility.</i>	<u>N</u> : 13 <u>Age</u> : 29 - 40 when diagnosed (age at time of interview not given) <u>Diagnosis</u> : breast cancer <u>Ethnicity</u> : 80% Caucasian; <u>Education</u> : 9/13 third-level educated <u>Relationship status</u> : not reported <u>Fertility status</u> : not reported <u>Parenthood status</u> : 5/13 no children <u>Inc criteria</u> : Diagnosed at 40 years or younger; diagnosed in previous 4 years (average time since diagnosis - 26 months); English-speaking. <u>Exc criteria</u> : none stated Women over 40, those in "extreme distress" or in palliative care.	<u>Design</u> : social constructionist, longitudinal <u>Recruitment procedure</u> : Displaying flyers at breast cancer events and support groups; purposive sampling - 13 chosen from 35 volunteers based on greatest need for support. <u>Data collection</u> : 3 x 1-1 interviews, 6 monthly over a 12-18-month period. 12/13 participants took part in all 3. <u>Data analysis</u> : interpretative social constructionism.	4 major relevant themes identified: 1. <i>Fertility</i> : Concerns about fertility increased over time for some; as 'normal' life resumed, the 'holes' left became apparent; some regrets about not utilising FP; some experienced unwanted pregnancies and feared recurrence. 2. <i>Contraception</i> : Concerns about safe, reliable contraception and particularly hormonal contraception; not reassured by doctors' reassurances of safety. Reluctance regarding partner vasectomy for fear of own death. 3. <i>Pregnancy</i> : Pregnancy for some was positive; some expressed anxiety regarding recurrence or death; balancing risks of recurrence with positive feelings associated with pregnancy – closing the book on cancer; forced forward and moving on. 4. <i>Breastfeeding</i> : All who conceived wished to breastfeed only from healthy breast. Breastfeeding associated with being 'good' mothers, doing the right thing for infants. Balancing the 'risk' of breastfeeding with achieving 'normalcy'.

Authors, date and geographical location	Quality Rating and Kappa Score	Research Aim(s)	Participants (sampling, inclusion and exclusion criteria)	Design and Method (recruitment procedure, data collection, data analysis)	Key Findings
Corney & Swinglehurst (2014) UK	Quality Rating: 18 (high) Kappa Score: .71	<i>To investigate the fertility-related experiences and concerns of young, childless women.</i>	<u>N</u> : 19 <u>Age</u> : 24-44 (20-41 when diagnosed) <u>Diagnosis</u> : breast cancer <u>Ethnicity</u> : 16/19 "British-born" <u>Education</u> : 15/19 third-level educated <u>Relationship status</u> : 10/19 single at diagnosis <u>Fertility status</u> : not reported; 7/19 underwent ART <u>Parenthood status</u> : not reported <u>Inc criteria</u> : diagnosed < 6 months ago; under age 45; childless but wanted children in the future. <u>Exc criteria</u> : none outlined	<u>Design</u> : qualitative descriptive <u>Recruitment procedure</u> : advertised through relevant charities and support groups. <u>Data collection</u> : semi-structured 1-1 interviews <u>Analysis</u> : thematic analysis (Braun & Clarke methodology)	3/9 major themes identified were relevant (others related to experience of care): 1. <i>Fertility-information and advice on pregnancy</i> : HCPs often open to discussions post-treatment but less so during treatment (focus on treating cancer); women shared concerns about recurrence, inability to raise children if this occurs and fears for future children's health. 2. <i>Worries about what the future might hold</i> : Worries about impact of treatment on fertility – many women uncertain about their fertility status; those who had preserved were less "preoccupied" about future fertility; younger women less worried – had time once hormonal treatment period ended; uncertainty made planning for the future difficult. 3. <i>Childless single women</i> : Women without partners "particularly vulnerable"; harder to find a suitable partner due to changes in appearance, fertility, life expectancy; sense of being less of a suitable partner given their experiences and possible 'limitations'.

Authors, date and geographical location	Quality Rating and Kappa Score	Research Aim(s)	Participants (sampling, inclusion and exclusion criteria)	Design and Method (recruitment procedure, data collection, data analysis)	Key Findings
Croson & Keim-Malpass (2016) USA	Quality Rating: 18 (high) Kappa Score: .615	<i>To gain a unique perspective of young women with cancer experiencing challenges with fertility and parenthood through analysis of blogs.</i>	<p><u>N</u>: 10. <u>Age</u>: 20-39. <u>Diagnosis</u>: unspecified. <u>Ethnicity</u>: not reported <u>Education</u>: not reported <u>Relationship status</u>: not reported <u>Fertility status</u>: not reported <u>Parenthood status</u>: not reported</p> <p><u>Inc criteria</u>: young women diagnosed with cancer in the USA; blog title or author bio identified blog is related to cancer experiences; mothers at diagnosis (n=6) or exploring motherhood and discussing (in)fertility (n=5).</p> <p><u>Exc criteria</u>: people living in other countries (and thus accessing other healthcare systems); women with stage 0 cancer (in situ)</p>	<p><u>Design</u>: qualitative descriptive</p> <p><u>Recruitment procedure</u>: Purposive sampling of blogs from larger parent study and cancer blog websites.</p> <p><u>Data collection</u>: analysis of public blog posts</p> <p><u>Analysis</u>: thematic analysis (Braun & Clarke)</p>	<p>Three of the five stages of the Kubler-Ross (1979) model of grief used to describe the experiences of aspiring mothers following cancer.</p> <p>1. <i>Denial</i>: Discussing “eggs” – avoidance of having to discuss the possibility of changes to their fertility and identity; evidence of women trying to regain a sense of normalcy and control the uncontrollable through pursuing fertility treatment, seeking information and greater certainty regarding their fertility or attempting conception.</p> <p>2. <i>Depression</i>: Anticipatory grief in those wishing for children; identity loss and loss of hope of the mother they thought they would be; becoming more aware and upset about the impact of treatment after it had ended; depression compounded by uncertainty of fertility status.</p> <p>3. <i>Acceptance</i>: Later acceptance of circumstances for some: exploring and creating new identities; finding ways to be optimistic and hopeful; hope for pregnancy after cancer. Some moved through stages “gracefully”, without expressions of anger or bargaining (other stages of grief).</p>

Authors, date and geographical location	Quality Rating and Kappa Score	Research Aim(s)	Participants (sampling, inclusion and exclusion criteria)	Design and Method (recruitment procedure, data collection, data analysis)	Key Findings
Dryden, Ussher & Perz (2014) Australia	Quality Rating: 19 (high) Kappa Score: 1	<i>To understand how female cancer survivors construct their fertility and their interactions with HCPs in relation to their fertility.</i>	<p><u>N</u>: 8 <u>Age</u>: 18-26 <u>Diagnosis</u>: various types of cancer (breast, brain, leukemia, lymphoma) <u>Ethnicity</u>: 5/8 Caucasian/'Australian' <u>Education</u>: 6/8 third-level education <u>Relationship status</u>: 4/8 single, 4/8 'partnered' <u>Fertility status</u>: 6/8 'uncertain' <u>Parenthood status</u>: none had children <u>Other demographic information</u>: all heterosexual; various religious affiliations reported.</p> <p><u>Inc criteria</u>: none specified but aim identified young female cancer survivors. <u>Exc criteria</u>: none identified.</p>	<p><u>Design</u>: social constructionist.</p> <p><u>Recruitment procedure</u>: Recruited from a large mixed-methods study examining the construction and experience of fertility after cancer. Participants responded to ads in cancer support groups, social media and hospital clinics.</p> <p><u>Data collection</u>: semi-structured 1:1 telephone interviews</p> <p><u>Analysis</u>: Foucauldian Discourse Analysis (FDA)</p>	<p>Three main constructions and experiences of fertility in the context of cancer were identified:</p> <p>1. <i>The inadequate woman: accepting the motherhood mandate</i>: Childlessness constructed as unnatural/pathological; motherhood essential component of femininity; women positioned selves as 'inadequate' and 'failed women' when unable to fulfil the social mandate, describing feelings of self-recrimination, fear, heartbreak, and loss. Infertility - social rather than biological failure; letting other down, particularly partners – should be able to 'give' them children. Fear of rejection or relationship difficulties due to this fundamental 'limitation'.</p> <p>2. <i>Adequate woman: resisting the motherhood mandate</i>: Some resisting the dominant discourse around motherhood; developing a sense of identity not tied to motherhood; focusing on other aspects of life and feeling more positive about the future.</p> <p>3. <i>Survival of the fittest: woman as genetically defective</i>: Hereditary flaws feared and reproduction seen as possibly irresponsible; pre-emptive guilt and self-recrimination for problems of future children. Alternative pathways to motherhood favourable.</p>

Authors, date and geographical location	Quality Rating and Kappa Score	Research Aim(s)	Participants (sampling, inclusion and exclusion criteria)	Design and Method (recruitment procedure, data collection, data analysis)	Key Findings
Gorman, Bailey, Pierce & Su (2012) USA	Quality Rating: 17 (high) Kappa Score: 1	<i>To explore the fertility and parenthood concerns of adolescent and young adult female cancer survivors.</i>	<p><u>N</u>: 22 <u>Age</u>: 16-35 (68% between 21 and 25). Average age at diagnosis - 16.8 (range - 6 months to 30 years) <u>Diagnosis</u>: various (lymphoma, breast, thyroid, bone, other). <u>Ethnicity</u>: 12/22 'white' <u>Education</u>: 13/22 third-level education <u>Relationship status</u>: 13/22 in serious relationship <u>Fertility status</u>: 13/22 'less fertile than peers', 3/22 infertile <u>Parenthood status</u>: 2/22 had children <u>Other demographic information</u>: 67% diagnosed in childhood or adolescence <u>Inc criteria</u>: none specified but aim described female cancer survivors. <u>Exc criteria</u>: none specified.</p>	<p><u>Design</u>: qualitative descriptive.</p> <p><u>Recruitment procedure</u>: clinic and community-based recruitment in San Diego area (half recruited through clinics).</p> <p><u>Data collection</u>: focus groups guided by a semi-structured guide</p> <p><u>Analysis</u>: data-driven inductive approach (form of thematic analysis)</p>	<p>6 themes were identified, 3 of which were relevant:</p> <p>1. <i>A hopeful but worried approach to fertility and parenthood.</i> Women described not being at the stage where they were 'trying' yet, but were willing to work hard to achieve parenthood and felt optimistic. Others also described concerns about the impact of treatment on their fertility. Some women delayed finding out about their fertility status due to fears of bad news, not wanting knowledge of the "demons under the bed".</p> <p>2. <i>Cancer diagnosis and related fertility problems introduce relationship challenges.</i> Difficulties regarding when and how to tell potential partners about history and possible infertility; worries about partners' ability to adapt if necessary (e.g. having to adopt); fears of negative impact of infertility on partners.</p> <p>3. <i>Decisions about parenthood are complicated.</i> Emotional and practical barriers to parenthood identified: fear of genetic inheritance, fear of recurrence, fear of death, fear of being financial instability, shorter window of fertility.</p>

Authors, date and geographical location	Quality Rating and Kappa Score	Research Aim(s)	Participants (sampling, inclusion and exclusion criteria)	Design and Method (recruitment procedure, data collection, data analysis)	Key Findings
Halliday, Boughton & Kerridge (2014) Australia	Quality Rating: 18 (high) Kappa Score: 1	<i>To explore the experience of “otherness” in the context of uncertain fertility, pregnancy and motherhood in young women treated for haematological malignancy during their reproductive years.</i>	<p><u>N</u>: 12 <u>Age</u>: 25-39 <u>Diagnosis</u>: haematological malignancy. <u>Ethnicity</u>: not reported <u>Education</u>: not reported <u>Relationship status</u>: 7/12 married, 3/12 single, 1/12 divorced <u>Fertility status</u>: 6/12 ‘uncertain’ <u>Parenthood status</u>: 2 had children prior to cancer; 2 had given birth since diagnosis; 2 pregnant at interview</p> <p><u>Inc criteria</u>: at least 1-year post-diagnosis; primary cancer treatment completed. <u>Exc criteria</u>: none stated.</p>	<p><u>Design</u>: phenomenological.</p> <p><u>Recruitment procedure</u>: advertisements on public online forums; purposive sampling of interested women.</p> <p><u>Data collection</u>: telephone or in-person 1:1 interviews</p> <p><u>Analysis</u>: van Manen’s method of phenomenological analysis (1990).</p>	<p>Two superordinate themes were identified:</p> <p>1. <i>Otherness as difference</i>: Sense of being different due to sense of being “defective”/possibly infertile; sense of disconnection from pregnant peers (mixed feelings towards them – envy, happiness, sadness); unsure whether they would continue to deviate from norms and expectations or would be able to share these experiences with their peers. Even when pregnancy was achieved, women still felt “othered”, as they were classified as “high-risk”. Some women made efforts to minimise the differences they felt through comparing selves with peers or focusing on positives.</p> <p>2. <i>Heightened temporal awareness</i>. Very conscious of time and time limits, particularly the timeframe for having children. The women spoke about their biological clock, the worry around which was heightened by their uncertain fertility. Pressure was felt not to leave it too late and to have children “on time”/in line with their peer group.</p> <p>Overall sense of women self-marginalising and self-othering due to feeling defective and different to peers, while trying to achieve normalcy and be “on time” with motherhood.</p>

Authors, date and geographical location	Quality Rating and Kappa Score	Research Aim(s)	Participants (sampling, inclusion and exclusion criteria)	Design and Method (recruitment procedure, data collection, data analysis)	Key Findings
Halliday, Boughton & Kerridge (2015) Australia	Quality Rating: 19 (high) Kappa Score: 1	<i>To explore the lived experiences of fertility, pregnancy and motherhood for young women who have received treatment for haematological malignancy in childbearing years and wished to have biological children.</i>	<p><u>N</u>: 12 <u>Age</u>: 25-39 <u>Diagnosis</u>: haematological malignancy. <u>Ethnicity</u>: not reported <u>Education</u>: not reported <u>Relationship status</u>: 7/12 married, 3/12 single, 1/12 divorced <u>Fertility status</u>: 6/12 'uncertain' <u>Parenthood status</u>: 2 had children prior to cancer; 2 had given birth since diagnosis; 2 pregnant at interview (<i>different motherhood information provided to study above, despite being same data – reason for inconsistencies unclear</i>). <u>Inc criteria</u>: at least 1-year post-diagnosis; primary cancer treatment completed. <u>Exc criteria</u>: none stated.</p>	<p><u>Design</u>: phenomenological.</p> <p><u>Recruitment procedure</u>: advertisements on public online forums; purposive sampling.</p> <p><u>Data collection</u>: telephone or in-person 1:1 interviews</p> <p><u>Analysis</u>: van Manen's phenomenological analysis (1990).</p>	<p>Two of three superordinate themes were relevant to the meta-ethnography:</p> <p>1. <i>Uncertain fertility as a liminal state</i>. Following treatment, women found themselves in a liminal state – not knowing whether they were fertile or not; reports of relief tinged with sadness at treatment possibly coming at the cost of motherhood. Sense of a lack of direction and seeking answers. The uncertainty and liminality experienced as being 'stuck'. Coping strategies identified included focusing on positives and maintaining hope for conception.</p> <p>2. <i>Pregnancy and Liminality</i>. Conceiving involved beginning to cross the threshold and transition to motherhood, while feeling uncertain whether they would succeed. High-risk pregnancies and fears of recurrence resulted in high anxiety and difficulties preparing for the child. Pregnancy described as providing closure but feeling uncertain. Liminality appeared to impact on women's ability to construct their identities, as they were unsure where they belonged and who they would become.</p>

Authors, date and geographical location	Quality Rating and Kappa Score	Research Aim(s)	Participants (sampling, inclusion and exclusion criteria)	Design and Method (recruitment procedure, data collection, data analysis)	Key Findings
Hauck Perez (2016) USA	Quality Rating: 18 (high) Kappa Score: 1	<i>To describe the views of female adolescents and young adult cancer survivors towards fertility preservation, and the impact it has had on their lives.</i>	<p><u>N</u>: 18 <u>Age</u>: 21-39 <u>Diagnosis</u>: various (lymphoma, breast, cervical, ovarian, multiple myeloma) <u>Ethnicity</u>: 16/18 'white' <u>Education</u>: all third-level education. <u>Relationship status</u>: 7/18 single at interview; 7/18 partnered; 4/18 divorced; <u>Fertility status</u>: 5 women underwent fertility preservation, others not reported. <u>Parenthood status</u>: 2 had children before diagnosis; 6 had children after diagnosis (1 by adoption);</p> <p><u>Inc criteria</u>: between 18 and 39 at time of interview; diagnosed during or after 2007; 15-39 when diagnosed; off treatment for at least 6 months. <u>Exc criteria</u>: none specified.</p>	<p><u>Design</u>: qualitative descriptive</p> <p><u>Recruitment procedure</u>: advertised at cancer support groups and social media in USA.</p> <p><u>Data collection</u>: 1:1 in-person or telephone interviews</p> <p><u>Analysis</u>: thematic analysis</p>	<p>Three overarching themes were identified:</p> <ol style="list-style-type: none"> 1. <i>Unpredictability of life.</i> Fertility after treatment - uncertain and unpredictable, accompanied by a sense of powerlessness; reluctance or anxiety about having children, related to fears for their own health and that of their children. Women who had preserved embryos or eggs - uncertainty regarding chances of success; fears of multiples. Efforts made to gain back control, including educating themselves about treatment and the impact on fertility. 2. <i>Loss: the toughest pill to swallow.</i> Fertility as a defining aspect of their female identity. The loss (or potential loss) of their fertility - feelings of loss and grief; feeling like "damaged goods" and "broken"; acceptance that life would be different; difficult, long journey. 3. <i>Relationships: struggling to meet societal and familial expectations.</i> Fears fertility issues meant they would struggle to find a partner; guilt due to feelings of anger and envy at peers who had children. Support was identified as key to coping. <p>Theme 4: <i>Moving on with life.</i> Adapting to "new normal" and having to adapt plans for a family.</p>

Authors, date and geographical location	Quality Rating and Kappa Score	Research Aim(s)	Participants (sampling, inclusion and exclusion criteria)	Design and Method (recruitment procedure, data collection, data analysis)	Key Findings
Kirkman (2014) Australia	Quality Rating: 19 (high) Kappa Score: .474	<i>To increase understanding of what it means to women of reproductive age to experience the threat to fertility and motherhood posed by cancer treatment.</i>	<p><u>N</u>: 10 <u>Age</u>: 26-45 (aged 25-42 when diagnosed) <u>Diagnosis</u>: breast cancer. <u>Ethnicity</u>: not reported <u>Education</u>: not reported <u>Relationship status</u>: 8/10 partnered <u>Fertility status</u>: 6/12 'uncertain' <u>Parenthood status</u>: 7/10 no children, one pregnant at interview. <u>Other demographic information</u>: not all women were cured/cancer-free (cancer-status not provided). <u>Inc criteria</u>: women aged 18-45; at least a year since diagnosis; <u>Exc criteria</u>: none stated.</p>	<p><u>Design</u>: narrative/constructivist.</p> <p><u>Recruitment procedure</u>: advertised through not-for-profit support organisation in Victoria, Australia.</p> <p><u>Data collection</u>: telephone or in-person 1:1 interviews.</p> <p><u>Analysis</u>: thematic analysis.</p>	<p>Six overarching, relevant themes identified:</p> <ol style="list-style-type: none"> 1. <i>Diagnosis as a pivotal life event</i>: Lives transformed by diagnosis; consumed by fears for mortality, concerns for fertility came later. Some forced to choose between survival and children. 2. <i>Robbed of time and choice</i>: Forced to make profound decisions about treatment quickly. Sense of powerlessness and loss of control to cancer. 3. <i>Significance of fertility</i>: Fertility as an essential part of being a woman; loss of fundamental part of selves; profound sorrow and loss. Investigated other pathways to motherhood e.g. fostering, adoption. 4. <i>Being a mother</i>: Assumption of becoming mothers; distress at losing capacity to breastfeed and delays caused by treatment; awareness of personal vulnerability; fears about genetic flaws. 5. <i>Narrative justification</i>: Rumination about decisions made and attempted to justify choices e.g. cryopreservation or not; termination when diagnosed; treatment choices. 6. <i>Life after breast cancer treatment</i>: Life and sense of self altered; losses not fully recognised – disenfranchised grief; particular challenges for single women. Use of the 'consoling plot' to cope and create meaning.

Authors, date and geographical location	Quality Rating and Kappa Score	Research Aim(s)	Participants (sampling, inclusion and exclusion criteria)	Design and Method (recruitment procedure, data collection, data analysis)	Key Findings
McDonald (2002) Canada	Quality Rating: 17 (high) Kappa Score: .74	<i>What is the lived experience of young adult women who have been diagnosed with early menopause following cancer treatment?</i>	<u>N</u> : 4 <u>Age</u> : 24-34 (16-23 when diagnosed) <u>Diagnosis</u> : 3 Leukemia, 1 Hodgkin's disease. <u>Ethnicity</u> : not reported <u>Education</u> : not reported, all employed. <u>Relationship status</u> : 2 married, 1 engaged, 1 in a committed relationship. <u>Fertility status</u> : infertile/post-menopausal <u>Parenthood status</u> : One woman adopting, one pregnant via egg donation, 2 – no children. <u>Other demographic information</u> : Residents of Canada (2) and USA (2). <u>Inc criteria</u> : diagnosed before age 20; between ages 21-32 at interview; diagnosed with early menopause and treated with hormone replacement therapy. <u>Exc criteria</u> : none specified.	<u>Design</u> : phenomenological <u>Recruitment procedure</u> : purposive sampling; advertised on internet support groups and via word of mouth. <u>Data collection</u> : two in-person or telephone 1:1 interviews per participant. <u>Analysis</u> : van Manen's (1990) method of phenomenological analysis.	Three main themes were identified: menopause, infertility and sexuality (<i>results and discussion together; lack of clear distinction between sections</i>). Cancer experienced as an 'intrusion' into their lives that meant women were required to adapt to early menopause and infertility. The women described having to reconcile with the changes to their bodies appearance and their sense of womanhood. They were required to find meaning in their new, altered world and reconceive of their embodied selves so they could engage with the world in a new way. A number of challenges for young women were identified, including the process of grief and loss involved in coming to terms with fertility loss for both them and their partners, the difficulties that arise between them and their peers as a result of not complying with norms and expectations and challenges with sexuality.

Authors, date and geographical location	Quality Rating and Kappa Score	Research Aim(s)	Participants (sampling, inclusion and exclusion criteria)	Design and Method (recruitment procedure, data collection, data analysis)	Key Findings
Thewes (2003) Australia	Quality Rating: 15 (medium) Kappa Score: .80	<i>To investigate the fertility- and menopause-related information needs of younger women with a diagnosis of early breast cancer.</i>	<u>N</u> : 24 <u>Age</u> : 26-45 (median age at diagnosis: 34) <u>Diagnosis</u> : breast cancer <u>Ethnicity</u> : 16/18 'white' <u>Education</u> : all third-level education. <u>Relationship status</u> : 10/24 single; 14/24 committed relationships. <u>Fertility status</u> : 9/24 experienced menopausal symptoms, others unsure. <u>Parenthood status</u> : 14/24 no children, 1/24 pregnant. <u>Inc criteria</u> : early stage breast cancer in previous 5 years; pre-menopausal at time of diagnosis; age 18 or older; commenced or completed adjuvant chemotherapy, radiotherapy and/or hormonal therapy. <u>Exc criteria</u> : none specified.	<u>Design</u> : qualitative descriptive <u>Recruitment procedure</u> : recruited through oncology clinic of a major teaching hospital. <u>Data collection</u> : focus groups <u>Analysis</u> : 'transcendental realism' thematic analysis (Miles & Hubermann, 1994)	5 themes identified, 4 of which were relevant: 1. <i>Perceived importance of receiving fertility- and menopause-related information.</i> Receiving information deemed 'extremely important', described as "my most major concern"; less important to some women but often became more important over time. 2. <i>Satisfaction with information provision.</i> Difficulties obtaining information; frustration at lack of clarity and uncertainty; many unclear on menopausal and fertility status. Some felt doctors deemed fertility less important than they did; some felt decision were made for them and felt a loss of control. 3. <i>Preferred timing and of information provision.</i> Information deemed necessary before adjuvant treatment commences so outcome can be changed, despite how overwhelming it can be. Information also deemed necessary later on. 4. <i>The psychological impact of unmet fertility- and menopause-related information needs.</i> A grieving process was identified that accompanied menopause and loss of fertility. Most women found support of families and friends, as well as HCPs, helped this process.

1.2.3 Analytic review strategy

1.2.3.1 Methodology

The value of synthesising qualitative research continues to be debated, with questions posed about whether findings generated in different contexts with different populations are transferable, particularly given the subjective nature of the qualitative research process (Britten et al., 2002; Bearman & Dawson, 2013). Despite this, there is growing recognition that synthesising qualitative research provides a more comprehensive, in-depth understanding of complex lived experiences and phenomena, which in turn can influence and inform theory, policy and evidence-based practice (Booth et al., 2016).

A number of established methods are used to synthesise qualitative research. This review utilised meta-ethnography, a well-established form of meta-synthesis increasingly used to synthesise healthcare research (Atkins et al., 2008). Meta-ethnography is an interpretive rather than integrative approach that employs a systematic synthesis process, going beyond identifying the themes in the individual studies and attempting to provide a deeper interpretation of the studies as a whole, while maintaining the properties and integrity of the original data (Dixon-Woods et al., 2005). The process of meta-ethnography involves the comparison, integration and analysis of individual qualitative studies, rather than a simple aggregation (Atkins et al., 2008). The seven stages involved in meta-ethnography outlined by Noblit & Hare (1988) are depicted in Table 1.4 and were followed for the purposes of this meta-ethnography.

Table 1.4

Description of the phases of meta-ethnography (Noblit & Hare, 1988)

Phases	Description
<i>1. Getting started</i>	Identifying how young women treated for cancer experience their fertility as an intellectual interest.
<i>2. Deciding what is relevant</i>	Conducting a systematic search for relevant qualitative studies (described in section 1.2.1)
<i>3. Reading the studies</i>	Reading the studies found in the systematic search carefully, paying particular attention to metaphors and themes identified by the authors to explain and/or describe women's experiences of their fertility.
<i>4. Determining how the studies are related</i>	Noting where the themes, categories and metaphors from individual studies were comparable (reciprocal) and contrasting (refutable), thus identifying possible relationships between studies.
<i>5. Translating the studies into each other</i>	Translating studies into one another. Mapping and examining relations between themes/concepts/metaphors within and between studies and identifying emergent themes.
<i>6. Synthesising translations</i>	Synthesising these translations by determining if some themes/concepts/metaphors could encompass other themes/concepts/metaphors, thus translating them into each other in the form of a 'reciprocal translation.'
<i>7. Expressing the synthesis</i>	Developing a new framework based on the interpreted data and translated into clinical recommendations.

1.3.2.3 *Carrying out the meta-ethnography*

Once the included studies had been finalised (stages one and two), the lead researcher read and re-read each paper to become familiar with the studies

(stage three). At this point, the characteristics of studies table (Table 1.3) was created, to support comparison and critical engagement.

The next step (stage four) involved ascertaining the relationships between the constructs in the individual studies (the term construct was employed as this is commonly used in meta-ethnographic studies to refer to concepts, ideas or themes arising from the data) (Britten et al., 2002). Each paper was individually re-read and the relevant constructs in the results and discussion sections of the studies were identified. The constructs were summarised on individual pieces of paper, along with the number of the corresponding paper (1 to 11) to ensure that they remained grounded in the original papers. Both first-order constructs (participants' quotes and 'common sense' interpretations) and second-order constructs (the original researchers' interpretations of the first-order constructs) were included (Schutz, 1963 in Britten et al., 2002). First-order constructs were linked with their corresponding second-order constructs, as reinterpretation of raw data without access to the original body of data was deemed inappropriate, as it might not identify the intended conceptual interpretation (Toye et al., 2014).

The next stage involved 'translating the studies into one another' (Noblit & Hare, 1988). This was achieved by comparing and organising the first- and second-order constructs into conceptual categories, or third-order constructs (the researcher's interpretation of the original researchers' second order constructs) (Britten et al., 2002; Toye et al., 2014). An index paper can be used to orient the analysis at this point, however Toye's method of comparison and categorisation of constructs was utilised instead, as none of the included papers were deemed to be 'classic' papers or appropriate to orient the translation (Toye et al., 2014). Images of this process are presented in Appendix E.

When the first- and second-order constructs had been organised into third-order constructs, the titles that encompassed all of the relevant underpinning constructs were generated. The original papers were then re-read to check the

suitability and fit. Based on the third-order constructs identified, a line of argument synthesis was conducted, whereby the themes from the individual papers were combined to develop a new interpretation of how women experience their fertility post-cancer treatment (Noblit & Hare, 1988). The third-order constructs will henceforth be referred to as 'themes', as this term described the phenomena identified more accurately.

1.3 Findings

The findings are comprised of two meta-themes: "*Am I still whole?*" – *the cost of survival*' and '*adjustment in the context of uncertainty*'. Within both meta-themes, seven sub-themes were identified. Table 1.5 depicts the meta-themes and sub-themes and Table 1.6 identifies the studies that endorsed each of the sub-themes.

The meta-synthesis identified how women experience an untimely diagnosis of cancer in the childbearing years as a "double trauma" (p. 1342, Dryden, Ussher & Perz, 2014). The shock of having a life-threatening illness is compounded by the realisation that their fertility could be compromised or lost because of the treatment they require to survive. While infertility is confirmed for some women, many women's fertility status is not, leaving them in a liminal state of uncertainty. This potential or confirmed loss of fertility has profound implications for women's identity, with many questioning whether they are still 'whole' if they have lost the capacity to have children. The women also experience both feared and actual losses in other areas in their lives, including their intimate relationships and peer groups. In attempting to come to terms with this uncertainty and loss, the women engage in a process of grieving and adjustment, where they negotiate their changed circumstances and find ways to come to terms with their altered bodies and lives.

Table 1.5

The review's meta-themes and sub-themes

Meta-themes	Sub-themes
“Am I still whole?” – the cost of survival	Derailing the trajectory
	Loss of the feminine identity
	Loss of relationships
	Regret and grief
Adjusting to loss and uncertainty	Uncertainty, liminality and hope
	Anxiety and ambivalence – to try or not to try?
	Acceptance and adjustment

Table 1.6

The links between the original papers and the identified sub-themes

Meta-themes	“Am I still whole?” – the cost of survival				Adjusting to loss and uncertainty		
Sub-themes	<i>Derailing the trajectory</i>	<i>Loss of the feminine identity</i>	<i>Loss of relationships</i>	<i>Regret and grief</i>	<i>Uncertainty, liminality and hope</i>	<i>Anxiety and ambivalence</i>	<i>Acceptance and adjustment</i>
Connell et al. (2006)	✓	✓		✓	✓	✓	✓
Corney & Swinglehurst (2014)	✓		✓	✓	✓	✓	
Croson & Keim-Malpass (2016)	✓			✓	✓	✓	✓
Dryden, Ussher & Perz (2014)	✓	✓	✓	✓		✓	✓
Gorman et al. (2012)	✓		✓	✓	✓	✓	✓
Halliday et al. (2014)	✓	✓	✓			✓	✓
Halliday et al. (2015)	✓	✓		✓	✓		
Kirkman et al., (2014)	✓	✓	✓	✓	✓	✓	✓
McDonald (2002)	✓	✓	✓	✓			✓
Hauck Perez (2016)		✓	✓	✓	✓	✓	✓
Thewes et al. (2003)	✓			✓	✓		✓

1.3.1 “Am I still whole?” – the cost of survival

This meta-theme explores women’s experiences of loss in relation to their threatened or lost fertility under four sub-themes: ‘derailing the trajectory’; ‘loss of the feminine identity’; ‘loss of relationships’ and ‘the grieving process’. Cancer treatment often comes at a high cost for women of childbearing age, with potential or confirmed infertility cited as one of their biggest concerns (Kirkman et al., 2014). Fertility is of central importance for most women, regardless of current relationship or motherhood status, future childbearing intentions or prognosis after treatment (Corney & Swinglehurst, 2014; Kirkman et al., 2014). Indeed, some women avoid certain treatments in an effort to preserve their fertility (Corney & Swinglehurst, 2014). Alongside threatened or lost fertility, a number of related losses are often experienced, particularly in relation to their feminine identity and relationships.

1.3.1.1 *Derailing the trajectory*

The occurrence of cancer in the child-bearing years is universally shocking for young women, immediately derailing the trajectory of their lives. Ten of the studies identify how women’s life plans are disrupted as they undergo treatment (see Table 1.6), with some feeling they are “*on hold*” (p. 747, Croson & Keim-Malpass, 2016) or “*cheated of time and choice*” (p. 505, Kirkman, 2014), unable to plan for the future (Corney & Swinglehurst, 2015; Halliday, Kerridge & Boughton, 2015). For many women, this disruption is particularly painful due to longstanding and previously taken-for-granted plans for the future.

It was a very significant thing for me because, you know, from the time I was about four years old, I knew I always wanted to have children. (p 506, Kirkman et al., 2014).

This unexpected disruption often leads to feelings of powerlessness and a sense of having lost control, where future plans are now dictated by cancer and doctors. This loss of control creates a sense of temporal disruption. Many women feel pressure from their 'biological clocks', particularly as they are often warned that their 'window of opportunity' for conception has likely narrowed (Gorman et al., 2012; Halliday, Boughton & Kerridge, 2014). Others feel frustration at being 'held back' by being unable to have children until treatment ends, which for some women spans a five-year period (Halliday, Boughton & Kerridge, 2014). Some women have a sense of being out of sync with, and older than, their peers because of their difficulties with infertility (Halliday, Boughton & Kerridge, 2015; McDonald, 2002).

Disruptions are sometimes easier to tolerate for younger women, who have often not attempted the transition to motherhood and feel they have time on their side (Dryden, Ussher & Perz, 2014), while older women feel a sense of urgency and pressure (Halliday, Boughton & Kerridge, 2014; Kirkman et al., 2014).

Halliday, Boughton & Kerridge (2014) provide a comprehensive description of this state of heightened temporal awareness and loss of control. It is worth noting, however, that both studies appear to be based on an analysis of the same interviews, raising questions about how the research was conducted and analysed. Furthermore, the other study that describes time pressures and loss of control (Gorman et al., 2012) lacks depth in the interpretation of findings. While these findings should therefore be treated with caution, there is evidence of disruption, loss of control and heightened temporal awareness in the majority of studies.

1.3.1.2 *Loss of the feminine identities*

Seven studies describe women feeling a sense of lost femininity (see Table 1.6). For many women, possible or confirmed loss of fertility lead to them feeling like ‘inadequate’ women, with many describing feelings of anxiety, distress and ‘heartbreak’ (Dryden, Ussher & Perz, 2014; Kirkman et al., 2014; Halliday, Boughton & Kerridge, 2014). This sense of inadequacy is posited to develop from an internalisation of the dominant discourse around women, with motherhood constructed as “...*central to the psychological and social completeness and fulfilment of women...*” (pg. 1347, Dryden, Ussher & Perz, 2014).

Feelings of inadequacy sometimes lead women to experience difficulties with their identities and self-esteem, as they are forced to question who they are now that a crucial aspect of their desired identity has been removed (Dryden et al., 2014; Kirkman et al., 2014). This sense of loss is particularly poignant for women with breast cancer, as part of their body that was associated with their femininity is also lost or changed by cancer (Dryden, Ussher & Perz, 2014).

I was heartbroken, I felt like I – it was just a feeling of being a failure as a woman in a way, because not only were my breasts diseased, it was also affecting my other things that I – like having children, which is something men can’t do, obviously... (p. 1347, Dryden, Ussher & Perz, 2014).

While Dryden, Ussher & Perz (2014) provide a comprehensive insight into this perceived loss of femininity, there is a lack of evidence of researcher reflexivity and few quotes to support the interpretations, which might imply a lack of validity. Despite these limitations, the experiences of lost femininity are also discussed in other papers, supporting the authors’ construction of these experiences.

1.3.1.3 *Loss of relationships*

Seven studies identify how the threat to fertility leads to women experiencing anticipated or actual losses in their close relationships (see Table 1.6). A number of women fear or experience rejection in their romantic relationships, both due to possible or confirmed infertility, and their precarious life expectancy (Corney & Swinglehurst, 2014; McDonald, 2002). Single women worry that they are no longer desirable as partners, seeing themselves as “*damaged goods*” (p. 42, Hauck Perez, 2016) and a potential “*burden*” (p. 9, Dryden, Ussher & Perz, 2014). This makes meeting new partners challenging, with questions around how and when to disclose their fertility issues and cancer history (Gorman et al. 2012). For women with partners, there are feelings of guilt or fear about the impact infertility might have on their partners and relationships, with some women fearing conflict and rejection due to being unable to provide children (Dryden, Ussher & Perz, 2014).

...I thought I was a pretty good catch... Now, it's like this is a whole side of me that's coming. It's like a package deal... I feel like a big part of the goal of marriage is to have kids. (p. 53, Hauck Perez, 2014).

Fertility difficulties can also lead to feared or actual losses in their wider social networks. Some women feel a sense of difference or ‘otherness’, as they feel unable to achieve the ‘normal’ developmental milestones of adulthood alongside peers, leading to feelings of exclusion and isolation (Halliday, Boughton & Kerridge, 2015). In this sense, infertility is seen as both a social and biological failure (Dryden, Ussher & Perz, 2014). Witnessing other women achieving these milestones sometimes evokes jealousy or guilt (Hauck Perez, 2016), while some women describe anger and frustration at friends’ insensitivity and lack of understanding regarding their fertility difficulties (Hauck Perez, 2016; McDonald, 2002).

While the loss of relationships was evident in numerous studies, it is worth noting that the Hauck Perez (2016) and McDonald (2002) studies are unpublished dissertations. While the inclusion of these findings is important, they should nevertheless be interpreted with some caution, as they have not undergone peer review.

1.3.1.4 *Regret and grief*

The initial focus at the time of diagnosis is usually survival, with fertility and FP being of secondary consideration (Thewes et al., 2003; Corney & Swinglehurst, 2014; Hauck Perez, 2016). While some women express satisfaction with their care, others experience healthcare professionals (HCPs) as “*blasé*” (p. 503, Thewes et al., 2003), “*insensitive*” or “*dismissive*” (p 76, McDonald, 2002), not recognising the importance of fertility.

While some women are not offered FP, those who do undergo FP do not regret their decision (Corney & Swinglehurst, 2014; Hauck Perez, 2016), with one study noting that women who underwent FP were noticeably “*less preoccupied*” by worries about their fertility (p 24, Corney & Swinglehurst, 2014). It is worth noting that the Corney & Swinglehurst study (2014), while strengthened by a relatively large sample of a homogenous group of women, lacks depth of interpretation in the nine themes presented, thus the nature of the participants’ experiences is under-articulated.

Many women describe sadness and regret at not having FP when they had the option (Connell et al., 2006; Halliday, Boughton & Kerridge, 2015), while some express resentment about not being offered FP (Corney & Swinglehurst, 2014). Others ruminate about whether they had done all that they could to preserve their chances of motherhood (Kirkman et al., 2014).

For many women, the sense of loss and regret results in a prolonged process of grieving, with many experiencing denial, sadness, anger and sorrow (Croson & Keim-Malpass, 2014; Hauck Perez, 2016; Kirkman et al., 2014; McDonald, 2002). Indeed, grief is identified in ten of the studies (Table 1.6). For those whose fertility status is uncertain, they experience “*anticipatory grief*” (p. 751, Croson & Keim-Malpass, 2014), while others experience “*disenfranchised grief*” (p. 508, Kirkman et al., 2014), as the significance of loss of fertility is underestimated or not recognised by HCPs or participants’ support networks. While all of the studies reviewed identified the significance of lost or threatened fertility to the participants, the participants were all self-selecting and therefore may have chosen to participate in a study about fertility due to the topic’s significance for them.

While fertility loss is devastating news for some women at diagnosis, others become more distressed over time. When treatment ends and they begin the process of returning to ‘normal’, the significance of the loss becomes apparent (Connell et al., 2006; Thewes et., 2003; Hauck Perez, 2014; McDonald, 2002). The relief of survival is therefore often tinged by sadness.

You don’t think that further out that’s my biggest regret because I could’ve had eggs frozen. It’s as time goes by and as life becomes a little bit more back to normal, as it can be, and you see the holes, the big holes that are left. (p 101, Connell et al., 2006).

1.3.2 Adjusting to loss and uncertainty

Anticipated or actual experiences of loss result in women engaging in a complex, sometimes delayed, process of adjustment in light of their changed circumstances. For some, this process involves the challenging task of weighing up the risks and benefits of having children while, for others, it involves adaptation

and acceptance of their altered fertility. This adjustment occurs in the context of continued uncertainty, as women's fertility status is often unconfirmed and cancer recurrence remains a possibility. This often compounds women's distress and anxiety. While the grief and adjustment process is unique to each woman, some women experience post-traumatic growth.

1.3.2.1 *Uncertainty, liminality and hope*

The women's sense of loss and grief is often compounded by uncertainty, both related to unconfirmed fertility and the possibility of cancer recurrence (Corney & Swinglehurst, 2014; Hauck Perez, 2016). Halliday, Boughton & Kerridge (2015) describe this uncertainty as a 'liminal state', whereby the women are unsure whether they are fertile or not. Eight of the studies in the review described some aspect of uncertainty (Table 1.6).

For some women, this liminal state is a source of anxiety and distress (Halliday, Boughton & Kerridge, 2015). Many women seek information and certainty to resolve this state of liminality. However, this is sometimes challenging to obtain, particularly as many women describe a lack of information regarding fertility, the significance of which is often minimised by HCPs (e.g. Gorman et al., 2013; Thewes et al. 2003). Other women find hope in this liminal state and avoid seeking confirmation of their fertility status, fearing the impact that confirmed infertility might have on their wellbeing (Gorman et al., 2013). Indeed, many women retain a sense of hope and optimism regarding their ability to have children, which helps them to carry on (Croson & Keim-Malpass, 2014; Gorman et al., 2013).

...Since I haven't been told to my face, "No, you can't have kids," I'm always optimistic about it... (p. 4, Gorman et al., 2013).

1.3.2.2 *Anxiety and ambivalence – to try or not to try?*

While a number of women have a strong desire to have children after cancer, both as a way of reclaiming their femininity and ‘closing the book on cancer’ (p. 103, Connell et al., 2006), many also express anxiety, guilt and reservations. This ambivalence, which was described in eight of the studies, is related to a number of fears, including the fear of cancer recurrence, not surviving to raise their children, passing on ‘defective’ genes, or the remnants of cancer treatment ‘damaging’ their children in utero (Gorman et al., 2013; Dryden, Ussher & Perz, 2014).

... the possibility of having kids for me is just this road that’s full of like landmines for me... (p. 9, Gorman et al., 2013).

Whilst most of the studies describe women’s experiences of an unfulfilled wish for children, Connell et al. (2006) also identified how pregnancy, particularly when unplanned, can be a significant source of stress, as it causes fears of recurrence or was seen as “*tempting fate*” (p. 102, Connell et al., 2006). With fertility seen as posing a potential risk to women’s mortality, effective and safe contraception is significant issue for many women. However, this was only discussed in one study (Connell et al., 2006). One participant, who experienced an expected pregnancy, described her distress:

I was horrified at the thought of being pregnant, really didn’t want to be pregnant because of the breast cancer. I really just thought that being pregnant would be a very bad idea. (p. 102, Connell et al., 2006).

Even when a desired pregnancy is achieved, this can be a period of stress and anxiety for women, as they are often classified as ‘high-risk’ and thus have to be regularly tested for signs of recurrence (Halliday, Boughton & Kerridge,

2015). Others fear delays in detecting a recurrence of breast cancer due to lactation (Connell et al., 2006).

Overall, the women are compelled to engage in a challenging balancing act, where they balance their desire for returning to 'normalcy' and motherhood with the anxiety associated with the perceived risks of pregnancy and motherhood, both for themselves and their children. In this sense, retained fertility is both desirable and a source of anxiety.

1.3.2.3 Acceptance and adjustment

While the grieving process is often protracted, nine studies describe some women adjusting to the changes to their fertility and accepting their losses (Croson & Keim-Malpass, 2013; Kirkman et al., 2014, Gorman et al., 2012). McDonald (2002) describes how the women begin a process of reconciliation with their changed bodies. Dryden, Ussher & Perz (2014) describes some women actively resisting the 'mandate of motherhood' and taking the position of 'adequate woman'. Kirkman et al. (2014) describes some women experiencing post-traumatic growth.

Women use a number of strategies in moving towards acceptance. For example, many reassess their priorities and focus on other aspects of their lives, such as work, relationships and religion (Dryden, Ussher & Perz, 2002; Kirkman et al., 2014). Others develop 'consoling plots', such as seeing their experiences as the result of fate, destiny or God's plan, or use 'narrative justification' as a way of accepting difficult treatment decisions (Kirkman et al., 2014). Although these narrative strategies were named by Kirkman et al. (2014), they are apparent in a number of other studies (e.g. McDonald, 2002; Hauck Perez, 2016; Dryden, Ussher & Perz, 2014). These strategies appear to help women to find meaning

and a sense of identity beyond the role of biological motherhood and 'cancer survivor', helping them to accept and make sense of their experiences.

I look at my life and o.k. I can't have kids but I'm still here, you know? And a lot of people aren't still here. So in the big scheme of things it's just a little hump in my life. (p. 81, McDonald, 2002).

Many women seek alternative paths to motherhood, with adoption and egg donation viewed favourably (Corney & Swinglehurst, 2014; Kirkman et al., 2014; McDonald, 2002; Gorman et al., 2012), particularly by women concerned about transmitting 'faulty' genes (Dryden, Ussher & Perz, 2014). One participant expressed pride in being able to mother children without families (Kirkman et al., 2014).

I think we feel that it's supposed to be this way. There is a kid out there that needs us. (p.68, McDonald, 2002).

Overall, the process of coming to terms with potential or confirmed fertility loss involves an individualised and protracted grieving process. While some women remain distressed, others progress to a point of acceptance, developing ways of tolerating the uncertainty of life after cancer, while finding a sense of identity and meaning beyond biological motherhood and cancer survival. While a number of studies described aspects of the women's grieving and adjustment process, only Connell et al. (2006) utilised a longitudinal design that described aspects of this experience over time.

1.4 Discussion

1.4.1 Summary of findings

This meta-ethnography sought to systematically evaluate and synthesise qualitative studies related to young women's experience of their fertility following cancer treatment. A total of 11 studies contributed to a line-of-argument synthesis, resulting in two meta-themes and seven sub-themes. The synthesis identifies how women often experience a sense loss in relation to their fertility, as well as related losses in anticipated life plans, their femininity identity and relationships. This sense of loss is often compounded by uncertainty regarding their fertility status, leaving women in a liminal state. Many women experience ambivalence about motherhood, attempting to balance to risks of motherhood with the anticipated benefits. While some women describe a prolonged process of grief, others appear to find ways of coming to terms with their losses and accepting their altered bodies and life trajectories.

1.4.2 Relation to previous literature

The first theme identified the profound sense of loss many women experience in relation to their potential or confirmed infertility. While previous reviews identified that women experienced psychological distress in relation to their fertility (Sobota & Ozakinci, 2014; Adams et al., 2011), the experience of grief and threats to identity and relationships has not been previously described. Furthermore, the experience of acceptance and adjustment as part of the grieving process had not been identified, although some of the processes women underwent to adjust to life after breast cancer described by Adams et al. (2011) could be understood as part of this adjustment process. As such, this review

provides a more detailed account of women's experience of loss, grief and adjustment in relation to their threatened or lost fertility after cancer.

The experiences of disruption and uncertainty identified in this review further emphasise the challenge that threatened fertility and an untimely disruption to childbearing can have on young women with cancer. While the experience of biographic disruption and liminality amongst cancer survivors is well-recognised (Barbour et al., 2013), it had not been described in previous systematic reviews in relation to fertility.

Finally, this review provides support for the findings of previous reviews (Goncalves, Sehovic & Quinn, 2011; Schmidt et al., 2016; Sobota & Ozakinci, 2014) around the ambivalence women feel about having children after cancer and the challenges women face in making decisions about childbearing. While this decision-making process was not the focus of the review, it was discussed in a number of the papers.

Overall, fertility-related issues appear to constitute an important aspect of cancer survivorship for women of childbearing age. Indeed, FP was recently identified as a key survivorship issue for young women in the USA (Angarita et al., 2016). While the growing recognition of the significance of fertility is welcome, this review identified how barriers to fertility discussions and FP remain for young women. Therefore, further work is required to improve women's access to fertility-related information and care.

1.4.3 Limitations

While synthesising qualitative research is becoming more commonplace, this approach is not without controversy. Indeed, some qualitative researchers argue that qualitative synthesis is "...epistemologically naïve and inappropriate"

(Britten et al. 2002, p.214) due to the impossibility of combining and generalising rich findings from studies carried out in different contexts. As such, the limitations of synthesising qualitative research from a variety of contexts should be borne in mind.

The sample of participants included in the review was somewhat heterogeneous, which may have introduced differences in experience. The differences in healthcare systems appeared to result in some differences in experience regarding fertility. For example, studies in the USA identified cost as a significant barrier to fertility treatment and a source of anxiety (e.g. Gorman et al., 2013; Hauck Perez, 2016), whereas this was not identified as an issue by the studies in the UK and Canada (e.g. Corney & Swinglehurst, 2016; McDonald, 2003), where this treatment is available under universal healthcare. In addition, while it was deemed important to include women with all types of cancer, rather than focusing solely on breast cancer, this may have introduced some differing experiences, as the women may have undergone different types of treatment, with differing impacts on fertility. Although this was not apparent in the findings, this possibility should be considered.

Meta-ethnography provides clear guidelines on the process of synthesis and steps were taken to ensure adherence to this process. Despite this rigour, the analysis necessitates a degree of creativity on the part of the researcher, as is the case for qualitative research in general (Whittlemore, Chase & Mandle, 2001). As such, it is likely that other researchers may have developed a different interpretation due to their knowledge, experiences and biases. While an audit trail was kept and the findings were checked with a research practitioner who works in the field of cancer, further confirmation of the validity of the findings would add to their credibility. When conducting a review, member checking with participants from the original studies is not possible. It may be useful, however, to seek feedback on the findings from experts by experience, for example by sharing the findings with a cancer support group. It may also be appropriate to contact of

authors of the original studies to seek feedback. This was not deemed possible in the limited timeframe of the doctoral thesis, but could be undertaken for future reviews.

1.4.4 Clinical implications

The review highlights a number of implications for clinical practice and healthcare policy. There is a growing recognition of the importance of fertility to young women with cancer. As such, evidence-based clinical practice guidelines and healthcare policy, reflecting the importance of addressing fertility-related issues from diagnosis into survivorship, are required. This would help to ensure that fertility and FP are discussed with all young women, regardless of relationship status, motherhood status or prognosis. While numerous guidelines are in place, a recent quality review found significant variations between recommendations and the majority were deemed lacking in quality (Font-Gonzalez et al., 2016). As such, greater consistency in clinical guidelines is required to support more appropriate and consistent fertility-related care.

The psychological and emotional support needs around fertility-related issues are also of significant importance, yet they are often under-estimated by HCPs. Perhaps understandably, HCPs often prioritise patient survival, however, given the increase in survival rates, issues that will affect patients' in the survivorship phase should also be considered and addressed. As such, training should be provided to raise awareness amongst HCPs regarding the importance of giving women adequate space and time to discuss their fertility-related concerns. It is also important that HCPs recognise that women are likely to require support throughout their cancer journeys into survivorship, as priorities and feelings regarding fertility may change over time. Support for women around decision-making around pregnancy may also be appropriate, as well as ensuring women have adequate information on the risks associated with pregnancy.

Efforts should also be made to reduce uncertainty, where possible, and provide emotional support for women when their fertility status cannot be confirmed, as uncertainty has been linked to excessive stress and difficulties with coping (Lazarus & Folkman, 1984).

While support from HCPs may be adequate for many women, some women appear to become “stuck” in the grieving process. For those experiencing prolonged grief, therapeutic support focusing on loss and bereavement may be appropriate. Third-wave talking therapies, such as Acceptance and Commitment Therapy (Hayes, Strosahl & Wilson, 2009), may be useful models for infertility-related distress and loss, as these models aim to support the process of acceptance. Accessing specialist bereavement counselling may also be useful. A number of models of grief, such as Kübler-Ross’ stages of grief model (Kübler-Ross & Kessler, 2005) or Worden’s tasks or mourning (Worden, 2018), may be helpful in supporting women to make sense of their experiences of loss and grief and to achieve a sense of acceptance and adjustment.

1.4.5 Future research

This review identifies how women experience grief, and sometimes adjustment and acceptance, in relation to their threatened fertility following cancer treatment. Although some studies described the processes and tasks women engage in to facilitate acceptance, further longitudinal research on how women’s distress may change over time, and the processes that enable women to adjust to their altered or uncertain fertility, is warranted. This understanding could help to inform the support provided to young women with cancer in the treatment and survivorship phases to promote psychological adjustment and wellbeing. The experiences of women in other cultures and in less developed healthcare system also requires further investigation, as do the experiences of male cancer survivors. Indeed, although there is some emerging research on

men's experiences of fertility following cancer, their perspectives are under-represented, as is the case with fertility research in general (Barnes, 2014).

1.5 Conclusion

Threatened or lost fertility is a significant issue for young women with cancer that can result in a prolonged experience of grief and loss. This experience is often compounded by uncertainty regarding their fertility status, and the challenging balancing act women are compelled to engage in to make decisions about whether to pursue parenthood goals. While some women find ways to come to terms with the uncertainty and loss associated with their altered fertility, others experience prolonged grief, sadness and regret. This review identified the importance of support related to women's fertility-related concerns and needs from diagnosis into survivorship. Further research is required to explore the processes that enable adjustment to threatened or lost fertility so that women can be supported to engage in these processes, thus encouraging acceptance and a greater sense of wellbeing.

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CHAPTER TWO

Exploring How Young Women with Polycystic Ovary Syndrome Experience their Intimate Partner Relationships.

Word count: 7,910 (excluding abstract and tables).

Prepared for submission to *Qualitative Health Research* (see author submission guidelines, Appendix F).

Abstract

Polycystic ovary syndrome (PCOS) is a common chronic endocrine condition associated with physical, psychological and sexual difficulties. This Interpretative Phenomenological Analysis study aims to understand the experience of being in intimate partner relationship as a young woman with PCOS. Seven young women from the UK took part in semi-structured interviews. Two superordinate themes emerged. The first superordinate theme describes how women felt undeserving of partners due to their threatened feminine identities. They feared losing their partners due to perceived 'failings' as women. The women engaged in battles to repair their feminine identities, seeking to meet idealised beauty norms and bear children. While the parenthood battle was shared with partners, the appearance-related battles were usually hidden. The second superordinate theme explores difficulties with sexual intimacy, both due to their perceived unattractiveness and, for some, failed conception attempts. The study highlights the importance of providing holistic psychosocial care to women with PCOS.

Abstract word count: 150

Keywords: Polycystic Ovary Syndrome; PCOS; intimate partner relationships; infertility; sexual intimacy; interpretative phenomenological analysis.

2.1 Introduction

2.1.1 Research aim and significance

This study aims to understand the experience of being in an intimate partner relationship (IPR) as a young woman with a diagnosis of Polycystic Ovary Syndrome (PCOS). PCOS is the most common endocrine disorder amongst women of childbearing age, affecting approximately one in ten (Bozdag et al., 2016). For the purpose of this study, an IPR is defined as a committed, monogamous relationship that involves emotional and/or physical intimacy (Miller, 2011).

PCOS is a chronic, heterogeneous condition, with physical symptoms including irregular or absent menstruation and ovulation, hirsutism, obesity and acne (Teede, Deeks & Moran, 2010). It is unclear what causes PCOS, but there are likely to be both genetic and environmental mechanisms resulting in hypothalamic-pituitary-adrenal disruption, insulin resistance and hormonal dysregulation (Norman, Dewailly, Legro, & Hickey, 2007). Common comorbid physical health problems include irritable bowel syndrome, type II diabetes and cardiovascular disease (Mathur et al., 2010; Norman et al., 2007). PCOS is also the leading cause of female infertility (Gorry, White & Franks, 2006).

Psychological difficulties are prevalent in women with PCOS (WwPCOS), including higher levels of depression, anxiety and body dissatisfaction (Cooney & Dokras, 2017; Himelein & Thatcher, 2006) and lower Quality of Life (QoL) and self-esteem (de Niet et al., 2010; Li et al., 2011). Indeed, PCOS may have a greater impact on psychological wellbeing than arthritis, epilepsy, diabetes or heart disease (Coffey, Bano & Mason, 2003). Psychological difficulties may be caused by an interaction between biological factors associated with PCOS, such as hormonal dysregulation, and distress associated with the symptoms of PCOS, such as hirsutism, obesity and infertility (Dokras et al., 2011; Farrell & Antoni,

2011; Hahn et al., 2005; Pastore et al., 2011). However, the psychological impact of infertility remains uncertain, with Tan et al. (2008) finding no correlation between an unfulfilled conception wish and psychological wellbeing in WwPCOS.

PCOS also appears to affect women's IPRs. Reductions in sexual satisfaction and functioning are common, with women experiencing themselves as less sexually attractive and believing their partners find them less sexually attractive (deFréne et al., 2014; Pastoor et al., 2018). While infertility can contribute to relationship conflict and sexual disruption in couples in general (Imeson & McMurray, 1996), the only study of couples with PCOS (DeFréne et al., 2014) found that women and their partners with unfulfilled conception goals and higher fertility issues report higher relationship satisfaction. Indeed, infertility can strengthen relationships in the general population (Phipps, 1993). Overall, while PCOS may affect women's experience of their IPRs, there are contradictions apparent in the existing literature.

2.1.2 Evaluation of previous literature

Most research on PCOS has been quantitative in nature, and has focused on physical symptoms and their management, or the prevalence of psychosocial difficulties. However, a small number of qualitative studies have investigated women's lived experience of PCOS.

A number of qualitative studies have identified how PCOS can threaten women's feminine identities. Kitzinger & Wilmott (2002) describe how WwPCOS experience their bodies and negotiate their identities. Using a feminist methodology, thirty WwPCOS in the United Kingdom (UK) were interviewed. Findings highlighted how, due to perceived violations of gender norms, including hirsutism, irregular menses and infertility, WwPCOS experience themselves as 'abnormal', with PCOS described as 'the thief of womanhood' (Kitzinger &

Wilmott, 2002). A phenomenological study involving twelve premenopausal WwPCOS in the United States (Snyder, 2006) also found women feel 'different' and like 'less of a woman', seeing themselves as 'deviant'. Furthermore, Keegan, Liao & Boyle (2003), using Foucauldian discourse analysis to explore hirsutism and psychological distress, found WwPCOS position themselves as 'freaks' due to internalised, idealised cultural norms. All three studies found women seek to conform with femininity norms by engaging in taxing regimes of hair removal and exercise to hide their 'abnormality', while continuing to feel guilt, shame and isolation.

While no qualitative studies have aimed to explore the sexual intimacy experiences of WwPCOS, findings from a number of studies have suggested that sexual intimacy may be an area of difficulty. Pfister & Romer (2017) interviewed twenty-one Danish women to explore the experience of hirsutism. As with previous studies, women felt 'different' and 'unfeminine'. However, they also felt sexually unattractive, where hairiness and attractiveness were described as mutually incompatible. Women's sexual relations were disrupted, as they hid their bodies from partners and sometimes avoided sex. They also feared new partners would not be interested in them. Hiding hirsutism from partners was also described by Kitzinger & Wilmott (2002). An Iranian study (Amiri et al., 2014) interviewed twenty-three women and also found that PCOS negatively affected women's sexual lives, both due to their perceived unattractiveness and fertility difficulties.

One qualitative study identified the importance of IPRs to WwPCOS. A UK study (Williams, Sheffield & Knibb, 2015) used photovoice technology to explore how PCOS affected women's subjective QoL. One of three themes identified the importance of support, where women described partners as invaluable sources of support, however this aspect of their experience was not explored in detail and further research into women's relationship experiences was recommended.

2.1.3 Rationale and research question

To date, most research on PCOS has focused on the physiological aspects of the condition. Where the psychosocial aspects have been explored, quantitative methodologies have largely been employed. While this research has highlighted the psychological and interpersonal difficulties WwPCOS may experience, nevertheless the nature of these experiences remains poorly understood and there are some contradictions in the literature. A small number of qualitative studies have explored the lived experience of WwPCOS. These studies elucidate the broader experience of the condition, and the experience of hirsutism in particular. While they provide some evidence that IPRs are important to WwPCOS, and that women may experience difficulties in their IPRs, there is little research directly exploring this aspect of their experience.

This study aims to address this gap in the literature by focusing on young women's experiences of their IPRs. Given the impact of PCOS on women's physical and psychological wellbeing, as well as their relationship and sexual functioning and satisfaction, it seems likely that PCOS will influence women's experiences of their IPRs. A better understanding of how young WwPCOS experience their IPR could help to identify the factors that contribute to the psychological, relationship and sexual intimacy difficulties that WwPCOS report. This understanding could help to inform the care and support provided to WwPCOS, with the aim of improving physical, psychological and interpersonal functioning and wellbeing.

The principal research question of this study is: what is it like to be in an IPR as a young woman with PCOS?

2.2 Method

2.2.1 Design

Given the experiential focus of the aim, an interpretivist epistemological position was employed, with a focus on phenomenology. Phenomenological research is concerned with providing a rich description of some aspect of subjective experience by attempting to 'return to the thing itself' and describe the experience as accurately as possible (Landridge, 2007). Rather than trying to access an objective reality, phenomenological researchers understand the world as being socially constructed. Interest lies in accessing subjective experiences and the meaning of these experiences, without assuming that these experiences or associated meanings will be shared by others in different contexts (Shinebourne, 2011).

The type of phenomenological analysis and design methodology used was Interpretative Phenomenological Analysis (IPA) (Smith, Flowers & Larkin, 2009). IPA's phenomenological approach aims to understand how individuals perceive and make sense of significant experiences of their lives, focusing on subjective experience, without imposing predefined categories or constructs (Smith, Flowers & Larkin, 2009). IPA is an interpretive methodology and is therefore theoretically grounded in hermeneutics, or how people make sense of their experiences. The researcher engages in a process of trying to make sense of participants' own efforts to make sense of their experiences, thus engaging in double hermeneutic interpretive process (Smith, Flowers & Larkin, 2009). IPA aims to describe participants' subjective experiences by highlighting both similarities and differences across participants, with an idiographic focus on the lived experience of particular people at a particular time (Allan & Eatough, 2016). IPA was deemed appropriate for this study as it provides a means of better understanding of the lived experience of being in an IRP as a young woman with PCOS.

2.2.2 Procedure

2.2.2.1 *Ethical procedure*

The study was designed and conducted in line with ethical guidelines from the British Psychological Society (BPS) in the Code of Ethics and Conduct (BPS, 2009) and Code of Human Research Ethics (BPS, 2010). Ethical approval for the study was sought from and granted by Coventry University Board of Ethics (Appendix G).

A number of ethical issues were anticipated and addressed. Informed consent was addressed by providing participants with a participant information sheet (PIS) and consent form before and during the interview (Appendix H and Appendix I). They were also informed that they could withdraw from the interview at any time, or withdraw their data for up to two weeks after. The possibility of harm, in particular distress or relationship acrimony following the interviews, was considered. All participants were made aware that confidentiality may be breached if significant safety concerns arose. A debrief sheet with information on relevant local sources of support (Appendix J) was provided to all participants after interviews. To ensure privacy, data were stored on a password-protected USB and laptop. After submission, transcribed data will be stored at the Department of Clinical Psychology in Coventry University until September 2023, when it will be destroyed.

2.2.2.2 *Materials*

A semi-structured interview schedule guided data collection (Appendix K). The schedule was developed by devising open-ended questions, in line with the principles of IPA. Themes addressed included the women's current health and wellbeing, their experiences of PCOS and the nature of their relationships. The

schedule was developed in collaboration with the research supervision team. The lead researcher sought feedback from two experts by experience (WwPCOS) on the content of the interview schedule, as well as the PIS and consent form, and the materials were adapted accordingly.

In line with the principles of IPA, the guide was applied flexibly and did not determine the course of the interviews, thus ensuring participants could provide comprehensive responses and direct the interviews, discussing the issues that they felt were relevant to the research question (Smith, Flowers & Larkin, 2009). Demographic information was also gathered using a short demographic questionnaire (Appendix L) to contextualise the experiences described, thus facilitating links to previous literature and enabling readers to consider transferability to other contexts (Allan & Eatough, 2016).

2.2.2.3 Recruitment

Purposive, non-probability sampling was employed to recruit participants, as the idiographic requirements of IPA necessitated a small, homogenous sample (Smith, Flowers & Larkin, 2009). This increased the likelihood of accessing shared experiences, while exploring convergences and divergences between participants. It also enabled the researcher to engage more deeply with the data and the complexity of the participants' lived experiences.

Participants were recruited by posting an advert (Appendix M) on the website and Facebook page of a UK-based charity that supports WwPCOS. Thirty-three women from across the UK, and one woman in Australia, contacted the lead researcher by email to express interest in participating. All of the UK-based women were sent a PIS and sample consent form. They were encouraged to ask questions and asked to confirm their eligibility based on the inclusion criteria outlined in the PIS. Twenty-seven women either did not reply, chose not

to participate or lived in parts of the UK that were not accessible to the researcher in the time frame of the study. Efforts were made to meet with all of the women who were interested in participating.

In total, seven participants were recruited and interviewed. This number was in line with recommendations of between four and ten participants for doctoral students (Heffernon & Gil-Rodriguez, 2011). Recruitment ceased when, in consultation with the supervision team, it was agreed that the interviews provided rich descriptions of a number of identifiable themes, within which there were similarities and divergences in experience.

2.2.2.4 Interview procedure

Individual, face-to-face interviews were the chosen method of data collection. An advantage of interviews is that they facilitate an in-depth exploration of an individual's subjective experience, as is required by IPA. Interviews also provide flexibility, which enables the participant and researcher to follow up on themes that arise, whether or not they were pre-empted by the interview schedule, which is also necessitated by IPA (Smith, Flowers & Larkin, 2009).

One cited disadvantage of interviews is the lack of objectivity into the phenomenon being investigated and the subsequent lack of generalisability (Willig, 2013). However, as IPA does not seek to provide an explanatory, generalisable account of an experience, objectivity was not sought in this study. Furthermore, rather than attempting to eliminate the impact of researcher bias, IPA accounts of the inevitable bias of the researcher on the data collection and analysis process (Smith, Flowers & Larkin, 2009).

Of the seven women who participated, three chose to meet at Coventry University and the other four were interviewed at home. The interviews took place between July and December 2018. Prior to the interviews, the PIS and consent form was reviewed and signed. Two digital audio recorders were used to record the interviews, in case one device failed. Following the interviews, the recordings were transferred to a password-protected USB and transcribed verbatim by the researcher at a later date, with identifiable information altered to ensure anonymity. Interviews lasted between approximately one hour and 90 minutes (mean of 72 minutes). On completion of the interviews, the demographic questionnaire was completed; participants were verbally debriefed and provided with the debrief sheet. Directly after the interviews, the demographic questionnaires were scanned and saved onto a password-protected USB and the physical copies were destroyed. All of the participants wished to receive a copy of the completed study.

2.2.3 Participants

2.2.3.1 Inclusion and exclusion criteria

Participants were eligible for the study on the basis of the criteria summarised in Table 2.1. These criteria were determined by the existing literature on WwPCOS and data from the Office of National Statistics (ONS) on the average childbearing age for women in the UK (ONS, 2017), as the literature suggested fertility-related issues were likely to be significant. Women unable to speak English to a high standard were excluded, given the importance of participants being able to discuss their experiences in detail. While the possibility of only including heterosexual women was considered, this was not deemed appropriate given the lack of literature identifying differences in experience based on this characteristic.

Table 2.1

Inclusion and exclusion criteria

Inclusion Criteria	Exclusion Criteria
A confirmed diagnosis of PCOS from a medical professional, with at least one clinical symptom (e.g. irregular or absent menstruation, hirsutism, male pattern balding, acne, obesity)	Unconfirmed PCOS PCOS without any symptoms
Women aged between 25 and 45	Women aged below 25 or above 45 People identifying as any gender other than 'female'
Women who have lived with their partners for at least a year	Women who are not living with their partners Women who have lived with their partners for less than a year
Can speak English fluently	Non-fluent English speakers; unable to speak English
Living in the UK	Non-UK habitants

2.2.3.2 *Participant characteristics*

Demographic information, as gathered in the demographic questionnaire, is presented in Table 2.2 and the narrative below. Demographic details were given in ranges so as to maintain anonymity. All of the women were assigned pseudonyms.

Table 2.2

Demographic information

Participant	Age	Relationship Status	Fertility-related experiences
Amelia	25-29	In a committed relationship for approximately 1-4 years	No children; had not attempted to have children.
Breda	30-34	Married, with her partner for over ten years	No children; previously experienced a miscarriage; had been trying for children for a number of years, without conceiving.
Christine	30-34	Married, with her partner for over ten years	No children; had not attempted to have children.
Diana	25-29	Married, with her partner for between 6 and 10 years	No children; possible previous miscarriage (unconfirmed); had been trying for children for a number of years, without conceiving.
Evelyn	25-29	Married, with her partner for over ten years	No children; had been trying for children for a number of years, without conceiving.
Freya	25-29	Married, with her partner for between 6 and 10 years	No children; had been trying for children for a number of years, without conceiving.
Grace	25-29	Married, with her partner for between 6 and 10 years	One biological child; had been trying for another child for a number of years, without conceiving.

Seven women were white British, while one was of mixed ethnicity; one woman was in a same-sex relationship and one woman underwent a number of years of unsuccessful fertility treatment. This information was not assigned to individual participants in order to preserve anonymity. Gendered pronouns and

terms used in the included quotes have also been changed to gender-neutral terms to preserve anonymity.

The women experienced a range of PCOS symptoms. All of the women experienced disruption to their menstrual cycle and/or fertility. All of the women also identified having unwanted hair, with five women identifying unwanted facial hair as a significant concern. Weight difficulties were an issue for six women, including difficulty losing weight. Four women experienced emotional and/or mental health difficulties that they associated with PCOS, although others spoke about these experiences at interview. Two women experienced acne.

2.2.4 Method of data analysis

2.2.4.1 *Steps of IPA*

The data from the semi-structured interviews were analysed using the iterative and inductive analytic process of Interpretative Phenomenological Analysis (IPA), as outlined by Smith, Flowers & Larkin (2009). The steps of this process are described in Table 2.3.

Table 2.3

Description of the steps of IPA

Steps	Description
<i>1. Reading and re-reading</i>	The researcher immersed themselves in the data by listening to the recordings and reading the corresponding transcripts a number of times, noting initial thoughts, interpretations and emotions related to the content in a Word document for each interview.
<i>2. Initial coding</i>	Each transcript was analysed line-by-line to identify objects of concern and things that mattered to the participants related to their experience of their IPRs, focusing on experiential content and associated meanings. Three types of codes were used, as suggested by Smith, Flowers & Larkin (2009): descriptive codes which described the content; linguistic codes that explored the use of language and conceptual codes that tentatively interpreted the data on a conceptual level.
<i>3. Developing emergent themes</i>	Based on reading and re-reading the initial codes, emergent themes were identified for each individual transcript. Emergent themes were recorded in the left-hand margin of the transcripts (for a sample transcript with initial coding and emergent themes, see Appendix N).
<i>4. Searching for connections across emergent themes</i>	The emergent themes were then collated, given labels, and the relationships between them considered. This process was carried out using post-it notes to enable flexibility of comparison and re-organisation. At this point, convergences and divergences were identified and intersubjective experiences and meanings were considered, with some adaptations made to the emergent themes. A graphic representation for each participant's experience was created to structure the emergent themes (for a sample graphic representation, see Appendix O). The emergent themes were also considered in light of previous research to consider their meaning in the wider context.
<i>5. Moving to the next case</i>	After a graphic representation had been created for the previous interview, the process described above was completed again for the next interview. In line with IPA's idiographic commitment, the researcher attempted to approach each interview without assumptions from previous interviews.
<i>6. Looking for patterns across cases</i>	The graphic representations for each case were compared to one another and the themes identified were considered. Existing themes were reconfigured and renamed as similarities and divergences between them were identified. The superordinate and subordinate themes were identified on this basis. Appendix P depicts part of this process. Excerpts from the interviews were selected to illustrate the identified themes.

2.2.4.2 *Credibility of analysis*

To improve the validity of the study's findings, quality checks were conducted (Mays & Pope, 2000). Both research supervisors monitored the analysis process and independently read interview transcripts that had been coded, alongside emergent themes. Feedback was integrated into the final themes, which were discussed with both supervisors. The lead researcher also attended peer group IPA support groups, where approaches to coding and thematic development were discussed and examples and challenges were considered.

2.2.4.3 *Researcher reflexivity*

IPA acknowledges the inevitable influence of the researcher's own values and assumptions on the research process (Smith, Flowers & Larkin, 2009). The impact of researcher bias was considered by using a bracketing interview with the lead research supervisor, aimed at identifying and exploring some of the researcher's values, preconceptions, assumptions and experiences that may influence the research process. This enabled the researcher to become more aware of how their value system, in particular their feminist values, and their own experiences of relationships, may influence the research process. The researcher also reflected on their 'outsider' status, due to not having a diagnosis of PCOS, and considered how this could influence the process. The researcher kept a reflective journal which focused on personal and epistemological reflections (Willig, 2013).

2.3 Findings

Two superordinate themes emerged as a result of the analysis, each with a number of subordinate themes (Table 2.4).

Table 2.4

Superordinate and subordinate themes

Superordinate Themes	Subordinate Themes
The undeserving partner	<i>"I feel like I've hit the jackpot with them and I feel like I'm letting them down..."</i> <i>"...your feeling of femininity... disappears out the window in an instant..."</i> <i>"...travelling the ups and downs together..."</i>
The impossibility of sex on a battlefield	<i>"I don't feel sexy; I don't feel in the mood..."</i> <i>"...it didn't feel enjoyable..."</i>

The first superordinate theme describes women's sense of being undeserving of their partners due to their threatened feminine identities. It also portrays their relentless battles to repair their femininity and comply with expectations. Within this theme, the first subordinate theme describes the women's perceived loss of their feminine identities due to perceived violations of appearance- and fertility-related gender norms, and their subsequent sense of relationship insecurity. The second portrays how the women worked to repair their feminine identities and comply with beauty expectations by concealing and managing their unruly bodies. The third then outlines the shared battles the women and their partners engaged in to fulfill their parenthood goals.

The second superordinate theme describes the difficulties women experienced with sexual intimacy, given their threatened feminine identities and the relentless battles to repair their femininity. The first subordinate theme portrays the difficulties the women experienced with sexual intimacy due to their internalised sense of unattractiveness, while the second depicts the incompatibility of sexual enjoyment and conception attempts.

2.3.1 The undeserving partner

The first superordinate theme describes how the women felt they were lacking as women and partners due to their threatened feminine identities. Their perceived 'failings' as women, both in relation to their appearance and fertility, undermined their relationship security, as they felt undeserving of their partners and feared rejection. All of the women battled against their unruly bodies, working to adhere to feminine norms. The battles with their appearance were often hidden from partners, whereas the parenthood battles were necessarily a shared endeavour. While the parenthood battles sometimes brought couples closer, actual or feared failure to repair their identities, and become 'proper' women, compounded the women's sense of insecurity and uncertainty in the long-term durability of their relationships.

2.3.1.1 *"I feel like I've hit the jackpot with them and I feel like I'm letting them down..."* (Grace, line 167-168)

The women's experiences of their IPRs were inextricably linked with their feminine identities. All of the women described their bodies failing to look or work as a woman's body should regarding their appearance and fertility. Most of the women felt they were letting their partners down, or unfairly burdening them, due

to their PCOS-related difficulties, while all of the women voiced fears that their partners would end the relationship.

Appearance-related difficulties included acne, unwanted hair and weight difficulties. The women reported unwanted facial hair to be most distressing issue, perhaps as this is seen as the most transgressive of gender norms, and the most difficult to conceal. All of the women also described fertility as a significant concern, due to their own parenthood goals and their duty to 'give' their partners and families children.

Many women were ashamed of their 'failings' as women due to perceived gender norm violations. All of the women's feminine identities appeared significantly undermined due to their inability to comply with expectations, as they described themselves as not "*proper*" women (Evelyn, line 387), "*in between*" (Grace, line 426), or "*a man that doesn't want to be a man*" (Freya, line 236). Many women felt guilty or humiliated by these perceived failings, describing a sense of responsibility and blame.

"... I've failed as a woman, I can't do it, because you feel, you feel like you've got an element of blame yourself because your body doesn't do what you want it to do and... you can't control it..."

(Evelyn, lines 278-280)

Some women found it difficult to go out in public with their partners because of their threatened identities, as they feared others would judge or ridicule them. Breda worried that other people would think her and her partner didn't quite 'fit'. Others feared their partners would be ashamed of them.

"...I don't want them to... be like... embarrassed when they take me out and then their friends and then think, "Oh God, you know what I mean, I'm

with some sort of beast". I don't want them to... to think like that so I do a lot to sort of... protect them from it."

(Diana, lines 584-587)

All of the women expressed fears that their partners could leave them due to their lack of femininity or PCOS-related difficulties. Indeed, some women appeared to feel this would be a fair response.

"There's been lots of times where I've said to them I feel like I'm letting them down, I want them to... well, I don't want them to (laughs), but you know I would understand if they... wanted to get a divorce and wanted to go find another wife or person or whatever who was capable of having children and who wasn't as mentally ill as I can be."

Breda (lines 126-129)

Grace and Amelia had both tried to end their relationships, perhaps in an attempt to avoid the anticipated rejection, saying their partners deserved better.

"...I have tried to end things with Sam a couple of times just because I've thought, they can do better than me, they can get a better person, they can get a better woman..."

(Grace, lines 286-288)

All of the women spoke to their partners about their feared rejection. Partners assured them that they did not intend to end the relationships, while some tried to alleviate the women's guilt and shame. Freya's partner provided assurances that they "didn't mind" and suggested that difficulties conceiving might be due to them. Most women found these assurances comforting and the conversations sometimes provided a deeper level of connection and emotional intimacy. However, many women questioned the veracity of the assurances or

worried they might change their minds. As such, the women's relationships often felt uncertain and precarious.

"I don't know what happens if I get to thirty and we haven't had a child. I don't know what that would be like, I don't know if they'll stay with me. That's... that's a genuine fear that I have in the back of my mind, that if I don't give them a baby, they'll leave me."

(Diana, lines 511-514)

All women described their partners as accepting, understanding and supportive, and whilst they appreciated this, nevertheless, some women voiced guilt about their need for support. Grace (line 102) feared that she had "conned" her partner. Some women also described feeling as though their relationships were unbalanced, as the support they required from their partners was unfair, and even burdensome.

"...I think they do understand but they shouldn't... I feel like they shouldn't have to. Like am... it's not fair, it's not just a one-person relationship, it's not just my relationship, it's their relationship too..."

(Amelia, lines 530-532)

Overall, the women's threatened feminine identities appeared to result in a power imbalance in their relationships. All of the women, to different degrees, felt as though they were not 'proper' women and thus not good enough for their partners. This left them in a precarious, uncertain place, as the security of their relationships was dependent on their partners accepting or 'tolerating' their 'flaws' and choosing not to leave, should they fail to become 'proper' women. While most partners worked to redress this power imbalance, assurances often appeared to fail to change how the women felt. Many women continued to feel guilty at the perceived burdens their partners endured because of their difficulties and feared they might eventually leave.

2.3.1.2 “...your feeling of femininity... disappears out the window in an instant...” (Christine, line 195)

All of the women in the study described efforts to repair their feminine identities and to adhere to idealised beauty norms. The perceived beauty norm violations, and their efforts to manage these violations, were often hidden.

All of the women described managing and concealing their appearance-related difficulties from their partners. Diana ‘protected’ her partner from her hirsutism, fearing they might be disgusted by her, while all participants described preventing their partners, and sometimes themselves, from seeing or feeling their bodies. Speaking about how conscious she felt about her stomach, Breda (lines 346-348) said, “...it can be quite hairy so I do have to manage that am... and I don’t like, I don’t necessarily like them seeing it or touching it or am... yeah, that, so I tend to wear a top a lot...”. Evelyn (line 407-408) also described her efforts to conceal her weight from her partner, saying, “...there’s absolutely no way I’m having a shower with that door open [laughs] because oh God they’ll see the rolls that I’ve got back here...”

The women also concealed management efforts from partners. While some management routines, such as those related to weight loss and hair removal on certain body parts, were shared with partners, many women avoided partners witnessing facial hair management. Perhaps facial hair and facial shaving are deemed more ‘masculine’ than other appearance-related issues, thus being the greatest threat to their femininity. Christine (lines 190-192) described her embarrassment:

"I was always incredibly mortified if my partner happened to come into the bathroom and I didn't expect them to. And see me with shaving foam on my face, shaving my face. Because that's not what a woman does..."

Even when couples are very close, managing unwanted facial hair is often concealed.

"... we are the kind of couple that if one of us is in the bath, the other one's sitting on the toilet talking to them, that's how close... we are as a friendship but... shaving my face is the only thing I'll lock the door for..."

(Grace, lines 417-420)

As such, the women's 'unfeminine' traits, and the obligatory management efforts, were a source of shame in their relationships, where they felt compelled to hide their perceived lack of femininity from partners. When these efforts were witnessed or known to partners, the women's feminine identities and relationship security were further undermined. All of the women shared this experience to different degrees.

2.3.1.3 *"...travelling the ups and downs together..." (Evelyn, line 638)*

While the appearance-related battles were often concealed from partners, the battles to achieve parenthood, and to repair this aspect of their feminine identities, were necessarily shared with partners. These battles still involved a level of secrecy however, as they were often hidden from others outside the couple. This shared battle sometimes resulted in emotional closeness due to the shared journey of hope and grief. This alliance is reflected in many women's use of plural personal pronouns when discussing this experience. Most couples had been unsuccessfully trying for children for a number of years. However, even the women who had not tried for children expressed fertility-related concerns.

The women described feeling a pressure to 'give' children to their partners and families, and a sense of guilt when they 'deprived' them of this. While most partners did not explicitly pressure the women, many felt pressured, either by their partners, their 'biological clocks' or their wider families. Indeed, for some women, such as Breda, a fear of failing to provide children was more anxiety-provoking than their own unfulfilled wish.

"...I think he would be an amazing parent so I think he deserves to have children and I don't know whether I can give that to him..."

Breda (lines 140-141)

The women differed in how they responded to pressure. Breda resisted perceived pressure to undergo fertility treatment, while Christine was comfortable not trying for children yet. Perhaps some women could more easily legitimise resisting or deferring parenthood expectations, given their young age, whereas the pressure to adhere to beauty expectations was more imminent and enduring. Others, such as Diana and Evelyn, appeared to struggle more under the pressure, describing guilt and anxiety at feared failures.

"... I feel the pressure off him, whether he intentionally or unintentionally gives it to me, I feel this pressure and this guilt... and this... well, if he was with someone else, he probably would have a baby by now..."

(Diana, lines 481-483)

Couples sometimes differed in their wishes regarding significant fertility-related issues. Breda and Christine differed from their partners regarding when they wanted to start 'trying' and Evelyn and her partner differed regarding their willingness to pursue adoption. Conflict did not always arise due to these differences. However, the women often felt guilty that their partners had to adapt or were unable to move forward, as they felt this could have been avoided had

they met 'proper' women. Indeed, the women all held the blame for their collective unfulfilled parenthood wish.

"...I feel I'm stopping... I feel I'm keeping my partner on hold. Because I feel if they were with anyone else, they might have a family by now."

(Freya, lines 515-517)

Conflict arose for some couples following failed conception attempts. Evelyn and Diana described conflict arising due to differences in how they and their partners managed distress. Indeed, the parenthood battle was described by Evelyn (line 137) as, *"the biggest strain"* on their marriage, saying, *"... each time when you find out that it hasn't worked and then... because you're upset, and your partner's upset, you get that sort of conflict there."* (Evelyn, lines 139-141).

Conversely, some couples were brought closer by the shared battle, as they were in the *"same boat"* (Evelyn, line 264). Breda (line 171) described how, while grieving a miscarriage, her and her partner *"... seemed to travel along the peaks and troughs at the same time..."*. This shared journey helped some women to cope with their distress and deepened the bond between them. As Evelyn (lines 250-251) said, *"... it brought us together quite a bit more because we... it was just us and it was our little secret if you like..."*

Overall, all of the women expressed some sense of blame and guilt for their unruly bodies and threatened feminine identities. They feared they were not good enough for their partners, as they did not look like 'proper' women and could not provide children, and that their partners might therefore leave. As such, a power imbalance existed in their relationships because of their threatened identities, where women felt a lack of agency regarding whether their relationships would endure. All of the women worked to repair their feminine identities, both by concealing and managing their unruly bodies, and, for some, trying to achieve parenthood goals. While partners were inevitably allies in the

parenthood battles, and greater closeness sometimes resulted, the appearance-related battles were often conducted covertly.

2.3.2 *The impossibility of sex on a battlefield*

Given how insecure the women sometimes felt in their relationships, and the battles they were fighting against their bodies, perhaps it is unsurprising that sexual intimacy struggled to flourish. Some women did not feel attractive and thus struggled to feel sexually confident or interested. For others, sex had become part of the protracted battle to conceive.

2.3.2.1 *"I don't feel sexy; I don't feel in the mood..."* (Freya, line 298)

A number of the women struggled to believe that their partners could find them sexually attractive. Indeed, some women appeared to expect their partners to find them unattractive, or even repellent. This expectation related to how the women felt their bodies looked and felt, as well as issues with irregular and heavy menses. As such, their relationships with their own bodies, and their harsh perceptions of themselves as unfeminine and unattractive, informed how they imagined their partners experienced them.

"... I don't understand how they're not disgusted with me, because I would be if I was them. Like I can't even look at myself when I get in the bath, I can't... I can't bear myself..."

(Grace, lines 252-254)

Many women described being sexually inhibited, hiding their bodies during sex, or not wishing to have sex at all, due to their shame at their lack of femininity.

Indeed, there was a sense that it would be impossible to be sexually confident, or to enjoy sex, without feeling attractive in themselves.

"I just feel really, really unattractive am... and I think that does impact on your intimacy because you don't... every woman is wanting to feel... attractive? To their partner or whoever, and... am... I think that just slowly kind of... eats away really. When you don't have that sexy, kind of feminine feel..."

(Christine, lines 230-233)

Although many women often did not feel like having sex because of their appearance, or due to pelvic pain (Breda and Evelyn), some felt compelled to force themselves. Breda (lines 86-87) said *"... it felt quite pressured for me to try and... force myself almost into being intimate with them because I didn't feel attractive?"* Perhaps sex was seen as a feminine duty, or an essential component of a functioning relationship, thus not having sex with their partners would have felt like a further 'failure'.

The degree of disruption to sexual intimacy varied. Amelia (line 335) described how her and her partner were almost never had sex, saying, *"I just can't deal with anybody, including myself, looking at me."* Freya (line 611-613), on the other hand, became more comfortable over time, saying, *"... it doesn't bother them. So I don't care about getting naked in front of them and being big as well. Like other partners I've had, I've kept my top on, you know, I've turned the lights off."* Therefore, while some women struggled to overcome their shame to allow themselves to be vulnerable with their partners, some women felt comfortable being seen and felt by their partners once trust had been established.

Many partners complimented the women on their appearance. While some women found this helpful, others struggled to trust their sincerity. A number of

women said their partners “couldn’t win”, as compliments were not accepted or helpful, however if they did not comment at all, this also evoked distress and frustration. While discussing her partner’s response to her facial hair, Diana (lines 559-562) said,

“... they’ll sometimes try and make me a joke out of it, which makes me feel worse because I know that they noticed it, or they’ll pretend like they don’t notice it and then I think, “God, are... are they just lying to me? Are they... or are they... not paying attention?” So it’s like a no winner for them really.”

Even when partners were complimentary, it did not seem to change how attractive the women felt. Indeed, a number of women rationally recognised that their partners found them attractive. However, they struggled to believe this, as it didn’t “compute” (Breda, line 294) with their own perceptions of themselves. This appeared to highlight the strength of the influence of gender norms on the women’s perceptions of themselves, where partners’ comments failed to change how they saw and felt about themselves.

“...it’s one of those things, isn’t it? Unless you believe... believe what someone is telling you, then... they can say it until they’re blue in the face, can’t they? But... it doesn’t make any difference.”

(Christine, lines 309-311)

While most of the women’s partners managed their anxieties about their appearance sensitively, others were described as less considerate. Diana, Evelyn and Grace described their partners suggesting they lose weight or remove hair, or making jokes about their appearance. Perhaps these comments derived from their partners’ internalisation of gender norms, or were a product of the power imbalance that had developed in some relationships. These women described the comments occurring either due to a lack of understanding or during

arguments. All of the women felt these comments further undermined their sense of attractiveness. While some women appeared to feel these comments were unfair, others seemed to feel they were warranted, perhaps due to their sense of being to blame for their 'failings' as women.

"My partner... [pause] doesn't comment so much but they they have commented a few times over the years that, Oh what look why don't you try to lose a bit of weight or... isn't it time that you shaved or... and comments like that and you're like, aw thanks for making me feel good..."

(Evelyn, lines 435-439)

2.3.2.2 "...it didn't feel enjoyable..." (Breda, line 77)

Fertility issues could also act as a barrier to sexual intimacy. For some women, the function of sex changed from being an enjoyable activity to a pressured, goal-oriented battle. Their sense of connection and enjoyment during sex was thus reduced, being replaced with a sense of pressure.

"...it just felt like really hard work and it didn't feel enjoyable ah... there was no kind of, "Oh, I'm enjoying spending this time with you". It's ah... "Oh, I think I'm ovulating today so let's have sex now." There was no am... spontaneity about it, apart from the pressured kind..."

(Breda, line 76-79)

Sex often reduced in frequency or became erratic due to irregular menstrual cycles, as women felt they were "*aiming in the dark*" (Breda, line 71), unsure if or when they were ovulating. Sex was also difficult for some couple due to the repeated cycle of attempts and failures. Describing the challenges with sexual intimacy between her and her partner, Diana (lines 619-620) said, "*I think... the disappointment of me having my period sort of puts... him off a bit*

and puts me off a bit... because it's like, oh, well I'm not pregnant again..." Freya anticipated the erosion of shared enjoyment due to conception attempts. She described trying not to "ruin the moment" by talking about conception during sex.

"I don't want to be one of these people where it... it takes over everything like, pull him into bed, y- like I'm ovulating now we've gotta do it sort of thing..."

(Freya, line 310-312)

Overall, women described how sexual intimacy in their relationships was eroded by their sense of being unfeminine and unattractive. Their relationships with their own bodies and their own sense of being unattractive, appeared to make it difficult, if not impossible, to feel attractive and sexually confident with their partners. Although some partners tried to assuage their insecurities, their perceptions of themselves often remained unchanged and most women continued to struggle to be sexually intimate with their partners. For others, their sense of unattractiveness appeared reinforced by their partners' insensitivity. In addition, for some couples, sexual intimacy was further eroded by the parenthood battle, where enjoyment was replaced by a sense of failing to meet a shared goal. Taken together, the battles to regain their feminine identifies made sex a stressful, pressured activity.

2.4 Discussion

2.4.1 Summary of findings

This research study aimed to understand how young women with PCOS experience their IPRs. The study employed an interpretative phenomenological approach. The analysis found that the women felt undeserving of their partners due to their threatened feminine identities. Their perceived failings as women led to feelings of guilt and shame and sometimes led to power imbalances in their

relationships, where the durability of their relationship was seen as dependant on them either repairing their femininity or their partners accepting their shortcomings.

In an effort to become ‘proper’ women, they engaged in relentless battles against their bodies to repair their femininity. While parenthood battles were undertaken with partners, the battles against their appearance were often conducted covertly, due to fears of partners witnessing their lack of femininity.

Sexual intimacy was difficult for all of the women to different degrees, as they struggled to be vulnerable and open with their partners, or to believe they could find them attractive. Although some partners tried to alleviate their insecurities, assurances often failed to alter the women’s perceptions of themselves. A number of women also described how the protracted parenthood battles further eroded sexual intimacy, as shared enjoyment was incompatible with repeated failed conception attempts.

2.4.2 Relation to existing literature

2.4.2.1 *Gender-norm violations and relationship security*

This study provides new information on how PCOS-related difficulties are experienced in women’s IPRs, and in particular how they impact on relationship security. Findings of previous qualitative research were replicated in relation to the negative impact perceived gender norm violations have on women’s feminine identities (Amiri et al., 2014; Keegan et al., 2003; Kitzinger & Wilmott, 2002; Pfister & Romer, 2017; Snyder, 2002). This study extends this understanding, however, by providing a richer description of how these gender norm violations undermine women’s relationship security, at times creating a power imbalance between them and their partners. While Pfister & Romer (2017) identified that

single women may avoid intimate relationships and fear rejection from potential partners, this study identified that women in long-term, committed relationships also carry this sense of insecurity and inadequacy. Findings by Pfister & Romer (2017) and Keegan et al. (2003) were supported, as the women's sense of 'wrongness' was felt most keenly in relation to hirsutism, and they engaged in similar covert management routines. However, acne- and weight-related insecurities, as well as insecurities related to fertility, were also described. As such, this study identifies how multiple aspects of the condition can threaten women's feminine identities and undermine their sense of security in their relationships, regardless of messages received from partners.

2.4.2.2 Fertility-related difficulties and relationship functioning

Fertility-related concerns were identified by all of the women. This study provides a clearer understanding of how infertility may be experienced in the IPRs of WwPCOS. As identified in previous research on infertility, women described experiencing distress, conflict, and bonding related to fertility difficulties in their IRPs (deFréne et al., 2014). This study provides a possible explanation for the higher levels of relationship satisfaction reported by WwPCOS with an unfulfilled conception wish (DeFréne et al.'s, 2014), as the shared nature of the parenthood battle was a source of bonding for some couples. It also helps to make sense of the psychological difficulties that some women experience related to fertility difficulties (Teede, Deeks & Moran, 2010), which may arise from, or contribute to, relationship conflict and insecurity, as well as the sadness, pressure and frustration that goes with failed conception attempts.

2.4.2.3 Sexual intimacy

This study also develops our understanding of young women's sexual satisfaction and functioning within their IPRs, which is often impaired in WwPCOS (Pastoor et al., 2018). As noted by deFréne et al. (2014), various PCOS-related difficulties can contribute to reduced sexual satisfaction, including appearance- and fertility-related difficulties. While previous qualitative studies described the role of hirsutism and fertility-related difficulties in difficulties with sexual intimacy (Amiri et al., 2014; Pfister & Romer, 2017), this study describes how both these issues, and other PCOS-related difficulties, including weight-related concerns, acne and pelvic pain, can act as barriers to sexual functioning and satisfaction. This study therefore provided an insight into the multiple, interacting factors that can contribute to difficulties with sexual intimacy for WwPCOS.

2.4.2 Limitations

Despite these contributions, a number of limitations were identified. The sample was limited in a number of ways. All of the women were aged between 25 and 33, thus falling at the lower end of the age range. While these findings provide an insight into the experiences of this age group, and comply with the homogeneity principles of IPA, women at different life stages (e.g. adolescence, end of childbearing years, post-menopause) may differ.

As noted by one participant, the inclusion of partners may have provided a deeper understanding of the experience of PCOS within an IPR. While including partners was considered, it was deemed appropriate to speak to women themselves first. Participants were self-selecting and recruited through a support charity, which may have biased the sample towards women experiencing concerns about their relationships. Furthermore, although this study provides an insight into the difficulties with sexual intimacy experienced by WwPCOS, this aspect of their experiences was under-explored with some participants, perhaps due the sensitive nature of the topic. As such, women's experiences of sexual

intimacy may not have been fully elucidated. Finally, due to the time constrictions of the doctoral thesis and the challenges of recruiting through a charity, member checking of findings was not conducted. While other validity checks were conducted, this may have strengthened the findings further.

2.4.3 Clinical implications

2.4.3.1 Services and clinical guidelines

Treatments for PCOS are generally aimed at managing physical symptoms, with little emphasis on the psychological or interpersonal impact of the condition (Norman et al., 2007). This study highlights the importance of holistic, specialist care for WwPCOS that includes psychological support for women and their families. At present, most of the UK does not have specialist PCOS services and WwPCOS often experience healthcare as fragmented and lacking in understanding (Gibson-Helm et al., 2014). Furthermore, clinical guidelines from the National Institute for Health and Care Excellence (NICE) for PCOS only relate to the use of metformin for women not planning pregnancy (NICE, 2013). As such, more comprehensive clinical guidelines and holistic services are required.

2.4.3.2 Therapeutic interventions

In line with previous research, psychosocial difficulties and distress were reported by the women in this study. Therapeutic interventions may be useful for some WwPCOS. Third-wave therapies aimed at promoting self-compassion, such as Compassion-Focused Therapy (Gilbert, 2010) or acceptance and adaptation, such as Acceptance and Commitment Therapy (Hayes, Strosahl & Wilson, 2009) may be particularly useful. While very little research into the clinical utility of psychological therapies for WwPCOS has been carried out, Rofey et al.,

(2009) provided provisional evidence for the effectiveness of Cognitive Behavioural Therapy. Couples' therapy or family therapy may also be useful where interpersonal difficulties are identified. Furthermore, a number of women described the usefulness of online or in-person peer support, as this helped to normalise their experiences and provided them with advice on managing the condition. Thus, women should be directed to online or local peer support services where possible. Indeed, WwPCOS have reported finding group counselling (Roessler et al., 2012) nurse-led peer support groups (Percy, Gibbs, Potter & Boardman, 2009) and online peer support (Holbrey & Coulson, 2013) helpful.

2.4.4 Further research

Given the homogeneity of the sample, further research exploring the relationship experiences of WwPCOS at different life stages, including adolescence and post-menopause, would be useful. Research with intimate partners or both partners together would also provide a clearer insight into the experiences of IPRs for couples where the woman has PCOS. Furthermore, research into other factors that may contribute to relationship difficulties in WwPCOS would be valuable, such as considering the women's attachment experiences, given that early relationship experiences are known to contribute to relationship security in adulthood (Collins & Read, 1990). Finally, further research specifically aimed at exploring WwPCOS' experiences of sexual intimacy would be valuable.

2.5 Conclusion

Using an IPA approach, this study explored how young WwPCOS experience their IPRs. The findings identified how young women felt undeserving

of their partners and feared rejection due to their threatened feminine identities. This sometimes led to a power imbalance in their relationships, where their partners were perceived as in control of whether their relationships endured. The women engaged in relentless battles to repair the feminine identities, which sometimes included partners as allies. The difficulties women experienced with sexual intimacy, and how these related to their perceived failings as women, were also explored. This study highlights the importance of holistic support for WwPCOS that accounts for their interpersonal context.

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CHAPTER THREE

Reflections on the research process – a personal account

Word count: 3,496 (excluding references).

3.1 Introduction – the importance of reflection

Over the course of the thesis, the importance of reflecting on the research process has become increasingly apparent to me. Indeed, reflection is a core competency in becoming an effective scientist-practitioner and researcher (British Psychological Society [BPS], 2014). Reflexivity is a particularly critical component of qualitative research, as it enables identification of how intersubjective elements may influence the research process (Finlay, 2002). This reflexive analysis aims to provide a greater contextual understanding of the research endeavour described in the review and empirical study, particularly given that both studies are qualitative in nature and thus have inevitably been shaped by my own biases, beliefs, values and experiences (Smith, Flowers & Larkin, 2009). I will reflect both on how I feel I may have influenced the research process, and on how the research has influenced me as an aspiring clinical psychologist. These reflections are informed by my reflective journal, which was kept throughout the research process, as well as by discussions with my supervision team.

3.2 Choosing the topic – why PCOS?

When I started the course, I was determined to undertake a quantitative research project. Previous trainees had warned me of the arduousness of qualitative analysis, and I felt more comfortable on the seemingly solid ground of positivism and ‘objectivity’. However, as I began to consider possible projects, it became apparent that my values were more aligned with a qualitative, interpretivist epistemology, where the idea of an objective reality is rejected, and instead experiences are understood to be socially constructed, constantly changing and unique to the individual (Chapple & Rogers, 1998). This aligns with my own belief that the use of generalisations to understand individuals has some

value, but is inevitably limited, given the complexity of each person. This project, and my immersion in the literature of qualitative research, has helped me to understand how essential both qualitative and quantitative research is to any field with a human component, and particularly clinical psychology.

Choosing a research topic was a challenge, and finalising my area of interest took quite a while. I had limited research experience prior to the course and did not know what field I wished to work in. As such, I was open to suggestions and when a project on PCOS was suggested, I was immediately interested. My interest in PCOS is likely influenced by a number of factors. Although I do not have a diagnosis of PCOS, I know a number of women who do, and their difficulty managing the condition has been apparent, as has the lack of understanding or support from both medical professionals and the wider public. When I started to research and discuss the topic with others, I also noticed how I sometimes felt uncomfortable. This discomfort highlighted to me the stigma that still surrounds the appearance- and fertility-related difficulties women with PCOS often experience. As such, I felt that providing a greater insight into the lived experiences of women with PCOS might help to enhance the understanding of the condition, with the hope that this would reduce the stigma, lack of understanding and lack of support women currently experience (Gibson-Helm et al., 2016).

When I spoke to women with PCOS about my developing project, a number of them described the challenge it posed in their intimate partner relationships. For some, the challenges were with sex and intimacy, whereas for others, their partners struggled to understand the condition. On reflection, the significance of women's intimate relationships made intuitive sense, given the impact on their appearance and fertility. However, when I consulted the literature, I was surprised by the lack of research attention it had received. I was therefore drawn to explore this experience in more detail. The choice of fertility-related difficulties amongst women after cancer was chosen later as a topic for the

systematic review, as there were parallels between this experience and those of the women in the empirical study.

3.3 The research process

3.3.1 The benefits and challenges of multiple hats

While working on this research study, I have also been developing my skills as a clinician. In many ways, the values and skills that underpin qualitative research compliment and overlap with my clinical skills. For example, the idiographic nature of IPA is somewhat similar to developing individualised psychological formulations that seek to understand the unique experiences and perspectives of each person, rather than imposing a pre-defined understanding upon them (Johnstone & Dallos, 2013; Smith, Flowers & Larkin, 2009). My clinical skills have also enabled me to create a good rapport with the women I have met, whereby I was able to create a space where they felt safe enough to discuss very personal matters. As such, my clinical skills often complimented my research skills, and vice versa.

There are also significant differences between the roles, and remaining in the role of the researcher was sometimes a challenge. Indeed, the challenge of being both a clinician and researcher is well recognised (Yanos & Ziedonis, 2006). Most of the time, it was refreshing and empowering to allow the women to tell their stories without imposing the agenda of an assessment or therapeutic session upon them. This became more difficult, however, when the women described significant distress or alluded to suicidal ideation, particularly given the ethical imperative to avoid causing harm to participants (BPS, 2014). At these points, it was challenging not to explore their distress in more detail or to attempt to formulate their experiences, despite this not being the focus or purpose of the interview.

As such, striking the balance between ensuring the safety of participants, while respecting their autonomy and the purpose of the discussion, was sometimes a challenge, and went against my instincts as a clinician. This dilemma may have impacted upon how I engaged with participants' distress. Thankfully, none of the women in the study presented with any significant risks and as such this ethical dilemma did not cause any significant issues. This experience has highlighted the possibility of this challenge in the future, however, and helped me to reflect on how I might balance the participants' right to autonomy with my professional responsibility to safeguard in the future.

3.3.2 *Parallel processes*

Throughout the research process, it became apparent that aspects of my experience of the thesis paralleled some of the women's experiences as captured in both the review and empirical study.

The women's protracted, relentless efforts to conceive and be 'proper' women felt similar to my own efforts to produce a viable research study that made me a 'proper' clinical psychologist. I also experienced a similar sense of uncertainty and liminality, where at times it felt difficult to believe that I would be able to bring the project 'to term'. While the pressure I experienced was less pervasive, in that the identity threat applied only to my professional identity, nonetheless the experience was often anxiety-provoking and exhausting. In a similar way to the women in the empirical study, this anxiety was compounded by a pervasive sense of guilt. While prioritising the research project, I had less time for my own partner, friends and family, and found it more challenging to focus on my clinical work.

The pressure that the women felt also paralleled my experience of the analysis. Throughout the project, I felt an increasing pressure to 'get it right' and

to do justice to the stories the women shared. I struggled to interpret the information they had provided, for fear of going beyond, or misrepresenting, their experiences. While this was achieved with support from my supervisors and the IPA guidelines (Smith, Flowers & Larkin, 2009), some discomfort remains. I regret not attempting to address this issue by checking my interpretations with my participants. Doing so meaningfully would have been challenging in the timeframe of the thesis, particularly due to delays in recruiting through a charity run by volunteers and having the writing block directly before submission. Furthermore, not seeking feedback can be justified, as the interpretative nature of IPA can mean member-checking is less suitable (Larkin & Thompson, 2009). Despite these justifications, I believe my values as a researcher, which privilege the voice of the participant, would lead me to prioritise member checking in the future. As discussed in my review paper, validity checks of this nature could also be considered for qualitative metasyntheses in the future.

Finally, the experience of acceptance, as described in the review, is one that I have found myself striving for in recent weeks. In my clinical practice, I often find myself drawing upon the ideas and strategies of Acceptance and Commitment Therapy (Hayes, Strosahl & Wilson, 2009), particularly when the circumstances of a person's life cannot be readily changed. As such, I have worked on applying these strategies to my experience of this thesis, where I have attempted to accept and tolerate the feelings of pressure, anxiety, uncertainty and guilt, while continuing to work towards my goal of submitting a 'good enough' piece of work. This experience has also helped me to recognise how challenging this process can be and just how much we sometimes ask of the people we see therapeutically. I hope that I will be able to bear this lesson in mind for my future therapeutic work.

Overall, the use of supervision and journaling was essential in helping me to identify where parallel processes were at play and when I might have been over-identifying with the women, or assuming understanding when in fact our

experiences were different. While these parallels are likely to have influenced the research process, I hope that my efforts to identify and reflect upon them has helped to prevent them from distorting my view and misrepresenting the data in both studies.

3.3.3 *“Do you have PCOS yourself?” – managing my ‘outsider’ status*

Throughout the research process, I became more aware of my ‘outsider’ status. Although I share many characteristics with the women who participated in the study, such as my gender and age, I do not share one characteristic that was key to the study – I do not have a diagnosis of PCOS. This issue of researcher insider/outsider status is long-debated in qualitative research, with some researchers suggesting that it is not possible to engage fully with a research topic unless you share the experiences you are researching (Merriam et al., 2001).

As such, I wondered how the women would feel about me and whether they would feel comfortable sharing their stories with me, particularly given the sensitivity of the topics being discussed. I also wondered if I would be able to engage with the information on the level that was required to fully make sense of it. A number of women in the study asked me if I had PCOS. I chose to disclose that I did not, as I felt it might negatively impact the rapport if I withheld information. Although this did not have any obvious impact on the level of engagement of participants, it is possible that they felt less comfortable speaking to a woman without the condition. While I recognise the value of shared experiences, I wonder if the similarities between us in terms of gender and age were sufficient. Although I do not have PCOS, I am subject to the same societal pressures as these women and so I have some understanding of the distress they experience at feeling like they are violating these norms. Indeed, many qualitative researchers acknowledge the false dichotomy between ‘insider’ and

'outsider' and believe a researcher can occupy both spaces simultaneously, as it is impossible to ever fully be one or the other (Dwyer & Buckle, 2009).

Through the use of supervision and reflective journaling, I hope that I have been able to identify how the differences in our experiences may have shaped my engagement with the women and the information they shared. I also hope that reflecting on the impact of my 'outsider' status may have helped to overcome the barriers this may have created for the women to share their stories with me.

3.3.4 Talking about sex

While planning and preparing for interviews, I was aware that I would likely be discussing sex with many, if not all, of the participants. My reflective journal at notes the difficulties I anticipated with having intimate conversations when reading the Pfister & Romer (2017) study on women's experience of hirsutism, as I felt jarred at times by the level of detail. Indeed, I wonder if my Irish Catholic upbringing, where sex and sexuality are uncomfortable topics that are usually avoided, may have influenced my discomfort. I discussed this in supervision and believed that I felt comfortable to speak openly with the women about this subject. Despite this, when listening back over my early interview recordings, I noticed how I often hesitated to use the word 'sex' or used euphemisms instead, such as 'intimacy'. This would imply that I was less comfortable discussing sex than I believed I was. Perhaps this is unsurprising, given that sex is still something of a sensitive subject, particularly between relative strangers, as is the nature of the researcher-participant relationship. While this issue was highlighted before my later interviews, and it felt easier for me to discuss sex over time, the woman in the study also used euphemisms and hesitated when elaborating on their sexual experiences.

For these reason, it seems possible that this aspect of the women's experiences may not have been fully explored. This may have been because they did not expect to discuss their sexual experiences, despite this being part of an intimate relationship for most people. As noted in the empirical paper, further qualitative research into the sexual experiences of women with PCOS would be beneficial to explore this aspect of their experience more comprehensively. Furthermore, this experience has helped me to reflect on the importance of preparing for discussions of sensitive topics and ensuring I can communicate in an open, comfortable way.

3.3.5 Being led by my own interests and agenda

During the interviews, I noticed that a number of women referred to traumatic childhood experiences. Although I did not pursue this in the interviews, as it was beyond the scope of the research question, I discussed it in supervision and wondered about recommending future research on this topic in the future.

I found myself becoming very interested in whether traumatic experiences may contribute to women developing PCOS, perhaps as a result of chronic over-activation of their stress response. Perhaps due to procrastination, I researched the biological mechanisms that underpin PCOS and felt surprised that no research into the link between PCOS and trauma had been identified. This interest is likely related to my interest in the impact of trauma on the body (e.g. Van der Kolk, 2015) and my belief that trauma-focused work and preventative interventions are undervalued in favour of medicalised, symptom-focused approaches.

As such, it is likely that my beliefs and clinical agenda meant I heard and prioritised this information, despite it being a passing comment for most women. It was only when it was suggested that discussing this information might alienate

the women who participated in the study that I realised I was likely pushing my own agenda and over-interpreting their comments by making premature links that could have been unhelpful to the PCOS community. This issue helped me to consider the importance of reflecting on how information is used and interpreted. In this case, although research into this area may help to further support the case for preventative interventions, the impact that this information may have for women with PCOS should be carefully considered.

3.3.6 Pathologising difference

I had begun to reflect on my reasons for choosing PCOS as a topic in the project development stage. However, the bracketing discussion prior to interviews helped me to reflect more deeply on how my values and experiences may have shaped my choice of topic, as well as my engagement with my participants and the information they shared. It also enabled me to reflect on how the information I have produced may be interpreted and used. These reflections were revealing and, at times, uncomfortable.

In particular, I became increasingly aware of how societal norms and values likely shaped my choice of topic. As a childless, unmarried woman of childbearing age, I am all too aware of the constant pressure on women to comply with the 'mandate of motherhood' (Russo, 1976), as well as beauty norms. As such, I can empathise with young women who unwillingly experience significant barriers to fulfilling these norms, as I am aware of the resulting pressure and sanctions. Indeed, in recent months, I have become increasingly aware of the constant implicit and explicit pressure on women to look slim, hairless and youthful, while also producing biological children. I have also been reading the work of feminist researchers who deconstruct the stereotypes surrounding 'childlessness' and identify the stigmatising and problematic assumptions and

descriptions that can be applied to women who do not comply with the motherhood mandate (e.g. Letherby, 2002).

When the project began, I felt compelled to develop a clearer understanding of the interpersonal difficulties women with PCOS experience. However, over the course of the project, I became frustrated with my choice of topic, as I felt I had unwittingly become a cog in the patriarchal, pro-natalist social machinery, where I was problematising difference and thus reinforcing the idea that there was something 'wrong' with these women.

I felt hypocritical - while I was espousing feminist, inclusive values, I was conducting research that could be interpreted as reinforcing potentially oppressive norms and expectations around what women 'should' be. I had hoped to explore experiences of difference and, depending on my findings, highlight how problematic narrow social norms can be, while also demonstrating that the spectrum of 'normality' is far broader than society often leads us to believe. However, I feared that my findings could be interpreted as further evidence of women's 'wrongness'. Indeed, this discomfort with the pathologising difference has also been growing in my clinical work, where I have become increasingly concerned about the impact of using diagnostic labels to describe distress and differences from cultural and social norms (Johnstone et al., 2018).

While I continue to grapple with concerns about pathologising difference, I recognise that the women who participated in the study viewed these issues as problems, and experienced significant distress as a result. As such, their voices and perspectives should be privileged over mine, and their stories should be shared. Indeed, I hope that our society will become more accepting, or at least more tolerant, of difference, so that the distress associated with these differences from the norm may lessen. However, I acknowledge that this acceptance is not the reality at present and difference still causes problems for many. As such, I hope that this project, rather than reinforcing these norms, will help to draw

attention to the distress women can feel when they fail to meet these narrow expectations, thus challenging and undermining the rigid rules that govern women's bodies.

More broadly, this dilemma about how societal expectations informed my research has helped me to reflect on the importance of considering why I am interested in researching a certain topic, and how the information I produce might be used. Going forward, I hope that I will remember these lessons and reflect upon these questions before undertaking research. There are lessons for my clinical practice too, where I hope that I am now more aware of the impact of implicit social pressures and values, thus enabling me to take a broader perspective on the factors that contribute to distress. Furthermore, it has helped me to reflect on the role clinical psychology can, and should, play in challenging unhelpful social norms and practices. Indeed, the importance of this is reflected in the increase in activism in clinical psychology, as seen by organisations such as Psychologists for Social Change. While their main focus is on highlighting the detrimental impact of austerity on wellbeing, it provides a helpful framework for challenging other unhelpful social issues, including oppressive gender norms.

3.4 Conclusion

As the thesis comes to an end, it has been helpful to reflect on how this experience has changed me, both as a clinical psychology trainee and a person. It has also been helpful to reflect on how I influenced the research process. Overall, I feel that my skills as a researcher have improved significantly. I am now more confident in my ability to critically appraise and conduct research, both in an academic and clinical setting. These skills will serve me well as a practicing clinical psychologist, where the ability to deliver and evaluate evidence-based practice continues to increase in importance. This experience has also made me

more aware of the challenges involved in conducting research, particularly in how time-consuming and laborious the process can be. Despite these challenges, this experience has helped me to feel more confident in taking on research projects as part of a clinical role, thus ensuring that research from clinical settings reaches the public domain.

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APPENDICES

Appendix A

Authors' Instructions for *Health Care for Women International*

Instructions for authors

Thank you for choosing to submit your paper to us. These instructions will ensure we have everything required so your paper can move through peer review, production and publication smoothly. Please take the time to read and follow them as closely as possible, as doing so will ensure your paper matches the journal's requirements. For general guidance on the publication process at Taylor & Francis please visit our [Author Services website](#).

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Health Care for Women International is an international, peer-reviewed journal publishing high-quality, original research. Please see the journal's [Aims & Scope](#) for information about its focus and peer-review policy.

Please note that this journal only publishes manuscripts in English.

Health Care for Women International accepts the following types of article:

- . Editorials, Articles, Commentaries

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Editorial: <http://tandfonline.com/doi/full/10.1080/07399330701848934> Style Guidelines

for Reviewers and Authors: http://www.tandf.co.uk/journals/authors/uhcw_reviewed.pdf

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Please note that long quotations should be indented without quotation marks.

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- . You can opt to include a **video abstract** with your article. [Find out how these can help your work reach a wider audience, and what to think about when filming](#).
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 - . For single agency grants
 - . This work was supported by the [Funding Agency] under Grant [number xxxx].
 - . For multiple agency grants

- . This work was supported by the [Funding Agency #1] under Grant [number xxxx]; [Funding Agency #2] under Grant [number xxxx]; and [Funding Agency #3] under Grant [number xxxx].
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Appendix B

Ethical Approval for Systematic Review from Coventry University Ethics Department



Certificate of Ethical Approval

Applicant:

Treasa McCarthy

Project Title:

How do young women who have been treated for cancer experience their fertility? A
meta-ethnography of qualitative research.

This is to certify that the above named applicant has completed the Coventry
University Ethical Approval process and their project has been confirmed and
approved as Low Risk

Date of approval:

11 January 2019

Project Reference Number:

P82431

Appendix C

Examples of systematic database search

Medline search, conducted 15.01.2019

▼ Search history (15)						VIEW LOG
<input type="checkbox"/>	# ▲	Searches	Results	Type	Actions	Annotations
<input type="checkbox"/>	1	exp FERTILITY/	38610	Advanced	Display Results More ▼	
<input type="checkbox"/>	2	exp Fertility Preservation/	1848	Advanced	Display Results More ▼	
<input type="checkbox"/>	3	exp Infertility, Female/	27303	Advanced	Display Results More ▼	
<input type="checkbox"/>	4	cancer.mp. or exp Neoplasms/	3308716	Advanced	Display Results More ▼	
<input type="checkbox"/>	5	oncology.mp.	87253	Advanced	Display Results More ▼	
<input type="checkbox"/>	6	radiotherapy.mp. or exp RADIOTHERAPY/	310669	Advanced	Display Results More ▼	
<input type="checkbox"/>	7	chemotherapy.mp. or exp Drug Therapy/	1443083	Advanced	Display Results More ▼	
<input type="checkbox"/>	8	1 or 2 or 3	65514	Advanced	Display Results More ▼	
<input type="checkbox"/>	9	4 or 5 or 6 or 7	4363998	Advanced	Display Results More ▼	
<input type="checkbox"/>	10	8 and 9	10183	Advanced	Display Results More ▼	
<input type="checkbox"/>	11	exp Attitude to Health/ or lived experience.mp. or exp Stress, Psychological/ or exp Adaptation, Psychological/	586524	Advanced	Display Results More ▼	
<input type="checkbox"/>	12	exp Health Knowledge, Attitudes, Practice/	100104	Advanced	Display Results More ▼	
<input type="checkbox"/>	13	11 or 12	586524	Advanced	Display Results More ▼	
<input type="checkbox"/>	14	10 and 13	311	Advanced	Display Results More ▼	
<input type="checkbox"/>	15	limit 14 to english language	299	Advanced	Display Results More ▼	

Web of Science search, conducted 17.01.2019

#	Count	Searches	Actions
# 12	256	#11 AND #10 <i>Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI Timespan=All years</i>	Edit
# 11	929,213	(ALL=(qualitative OR interview* OR focus group*)) AND LANGUAGE: (English) <i>Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI Timespan=All years</i>	Edit
# 10	2,400	#8 AND #7 Refined by: DOCUMENT TYPES: (ARTICLE) <i>Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI Timespan=All years</i>	
# 9	3,015	#8 AND #7 <i>Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI Timespan=All years</i>	Edit
# 8	1,933,269	(TS=(wom?n OR female*)) AND LANGUAGE: (English) <i>Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI Timespan=All years</i>	Edit
# 7	5,036	#6 AND #4 <i>Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI Timespan=All years</i>	Edit
# 6	14,180	#5 AND #1 <i>Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI Timespan=All years</i>	Edit
# 5	2,733,330	#3 OR #2 <i>Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI Timespan=All years</i>	Edit
# 4	9,901,024	(TS=(experience OR lived experience OR meaning OR impact OR response* OR perception* OR adjustment* OR adaptation* OR distress OR coping OR psychosocial need*)) AND LANGUAGE: (English) <i>Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI Timespan=All years</i>	Edit
# 3	541,054	(TS=(chemotherap* OR radiotherap*)) AND LANGUAGE: (English) <i>Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI Timespan=All years</i>	Edit
# 2	2,582,892	(TS=(cancer OR oncolog* OR neoplasm* OR malignan* OR tumour*)) AND LANGUAGE: (English) <i>Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI Timespan=All years</i>	Edit
# 1	166,932	(TS=(fertility* OR infertilit* OR fertility preservation OR reproductive issue* OR reproductive abilit* OR premature menopause)) AND LANGUAGE: (English) <i>Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI Timespan=All years</i>	Edit

Appendix D

CASP Quality Assessment Scoring Grids

Researcher's own scores:

	1. Connell (2006)	2. Corney (2014)	3. Croson (2016)	4. Dryden (2014)	5. Gorman (2012)	6. Halliday (2014)	7. Halliday (2015)	8. Kirkman (2014)	9. McDonald (2002)	10. Hauck Perez (2016)	11. Thewes (2003)
1. Was there a clear statement of the aims of the research?	1	2	2	2	2	1	2	2	2	2	2
2. Is a qualitative methodology appropriate?	2	2	2	2	2	2	2	2	2	2	2
3. Was the research design appropriate to address the aims of the research?	2	2	2	2	2	2	2	2	2	2	2
4. Was the recruitment strategy appropriate to the aims of the research?	1	2	1	2	2	2	2	2	1	2	1
5. Was the data collected in a way that addressed the research issue?	2	2	2	2	2	2	2	2	2	2	2
6. Has the relationship between researcher and participants been adequately considered?	1	1	1	1	0	1	1	0	2	1	0
7. Have ethical issues been taken into consideration?	2	2	2	2	2	2	2	2	2	2	1
8. Was the data analysis sufficiently rigorous?	2	2	2	2	1	2	2	2	1	1	1
9. Is there a clear statement of findings?	2	1	2	2	2	2	2	2	1	2	2
10. How valuable is the research?	2	2	2	2	2	2	2	2	2	2	2
Total score	17	18	18	19	17	18	19	19	17	18	15

Reasons for scores of 0 or 1

Connell (2006):

- Question 1 – aims stated were vague (regarding women's needs and concerns) and did not specify that these concerns were related to fertility.
- Question 4 – participants were selected based on their reported support needs, rather than their issues related to fertility
- Question 6 – limited references to researcher reflexivity

Corney (2014)

- Question 6 – no reference to the relationship with participants or researcher reflexivity
- Question 9 – lack of reflection on limitations

Croson (2016)

- Question 4 – data was gathered from a subset of data gathered for a different purpose
- Question 6 – no specific reference to their own biases, although reflective journaling was used

Dryden (2014)

- Question 6 – no reference to researcher reflexivity

Gorman (2012)

- Question 6 – No reference to the researcher-participant relationship or attempts at researcher reflexivity
- Question 8 – Lack of development of the themes, with little interpretation beyond a short description and the use of long quotes.

Halliday (2014)

- Question 1 – no clear statement of aims or a research question, rather the study's outcomes were described
- Question 6 – some references to use of researcher reflexivity

Halliday (2015)

- Question 6 – little reference to use of researcher reflexivity

Kirkman (2014)

- Question 6 – no reference to researcher reflexivity or the relationship between researcher and participants

McDonald (2002)

- Question 4 – a more comprehensive recruitment strategy may have resulted in more than 4 participants being recruited.
- Question 8 – lack of rigour in analysis
- Question 9 – findings not clearly presented as themes

Hauck Perez (2016)

- No reference to researcher reflexivity or the use of strategies to enable reflection.

Thewes (2003) –

- Question 4 - Only women who were patients of an oncology department in a major teaching hospital were recruited, thus limiting the generalisability of findings (particularly as these women are likely to have a different level of access to information than women not being seen in an oncology department)
- Question 6 – no reference made to researcher reflexivity or the use of strategies to enable reflection.
- Question 7 – no reference to seeking or being granted ethical approval; some references to ethical considerations being made (e.g. regarding who to interview)
- Question 8 – little information provided on the analysis process or the method of analysis employed; member checking only conducted with two of the eight interviewees; no information about how the focus group and interview data were managed – separately or in the same analysis

Colleague's scores:

	1. Connell (2006)	2. Corney (2014)	3. Croson (2016)	4. Dryden (2014)	5. Gorman (2012)	6. Halliday (2014)	7. Halliday (2015)	8. Kirkman (2014)	9. McDonald (2002)	10. Hauck Perez (2016)	11. Thewes (2003)
1. Was there a clear statement of the aims of the research?	1	2	2	2	2	1	2	2	2	2	2
2. Is a qualitative methodology appropriate?	2	2	2	2	2	2	2	2	2	2	2
3. Was the research design appropriate to address the aims of the research?	2	2	2	2	2	2	2	2	2	2	2
4. Was the recruitment strategy appropriate to the aims of the research?	1	2	1	2	2	2	2	2	1	2	2
5. Was the data collected in a way that addressed the research issue?	2	2	2	2	2	2	2	2	2	2	2
6. Has the relationship between researcher and participants been adequately considered?	2	0	2	1	0	1	1	0	2	1	0
7. Have ethical issues been taken into consideration?	2	2	2	2	2	2	2	2	2	2	1
8. Was the data analysis sufficiently rigorous?	2	2	2	2	1	2	2	2	2	1	1
9. Is there a clear statement of findings?	2	1	2	2	2	2	2	2	1	2	2
10. How valuable is the research?	2	2	2	2	2	2	2	2	2	2	2
Total score	18	17	19	19	17	18	19	18	18	18	16

Reasons for scores of 0 or 1

Connell (2006):

- Question 1 – lack of clarity regarding the aim, fertility not specified
- Question 4 – not all participants were interviewed at follow-up, and those that were interviewed were selected based on their reported support needs, rather than their reproductive concerns which was the purpose of the study

Corney (2014)

- Question 6 – nothing about researcher reflexivity or potential bias/influence
- Question 9 – some methodological limitations have been noted but the researcher hasn't critiqued the credibility of their findings

Croson (2016)

- Question 4 - data was gathered from a subset of data gathered for a different purpose

Dryden (2014)

- Question 6 – some reference to possible researcher influence (e.g. anonymity via telephone) but no explicit statements about reflexivity

Gorman (2012)

- Question 6 – nothing about researcher reflexivity or potential bias/influence

Halliday (2014)

- Question 1 – the aims are worded as findings so no clear statement is given in the introduction, although the abstract and methods refer to aims
- Question 6 – some reference to credibility checks but no explicit statements about reflexivity or possible bias/influence

Halliday (2015)

- Question 6 – some reference to credibility checks and reflexivity but no explicit statements made

Kirkman (2014)

- Question 6 – nothing about researcher reflexivity or potential bias/influence

McDonald (2002)

- Question 4 – recruitment strategy lacking in rigour.
- Question 9 – presentation of findings lacked a cohesive structure

Hauck Perez (2016)

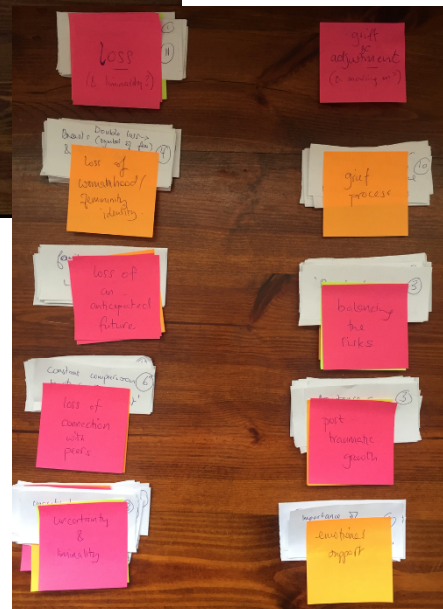
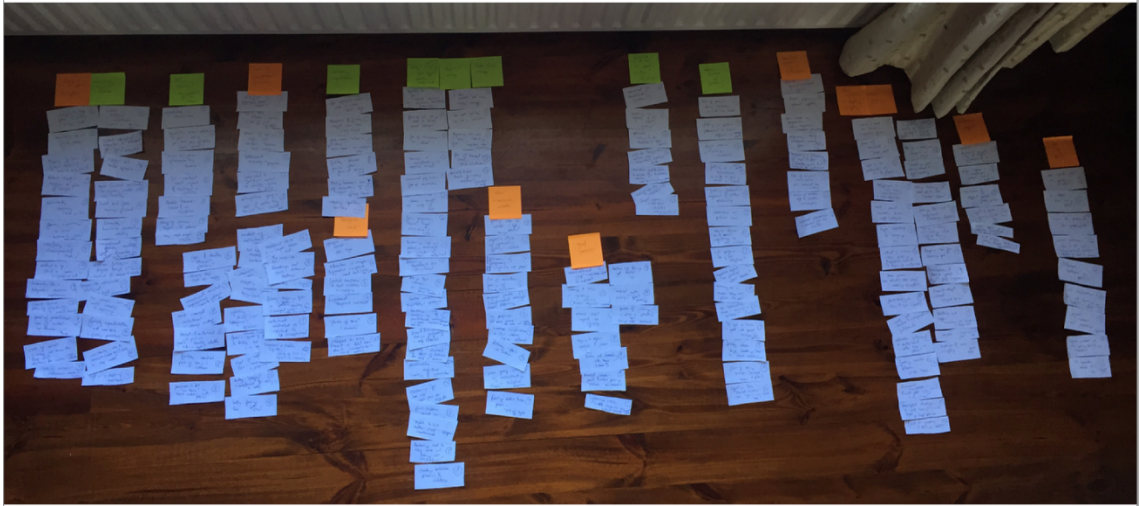
- Question 6 – section on validity checks but no explicit statements about reflexivity or possible bias/influence
- Question 8 – no validity checks of findings

Thewes (2003)

- Question 6 – nothing about researcher reflexivity or potential bias/influence
- Question 7 – references to information sheet and consent form, but no other ethical considerations/approval
- Question 8 – mention of analysis method by Miles and Huberman, but no detailed information about the analytic steps taken by the authors

Appendix E

Images of Meta-ethnography Analysis



Appendix F

Author's Instructions for *Qualitative Health Research*

3.4 Permissions

Authors are responsible for obtaining permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere. For further information including guidance on fair dealing for criticism and review, please visit [our Frequently Asked Questions](#) on [the SAGE Journal Author Gateway](#).

4. Preparing your manuscript

4.1 Article Format (see previously published articles in QHR for style):

- **Title page:** Title should be succinct; list all authors and their affiliation; keywords. Please upload the title page separately from the main document.
- **Blinding:** Do not include any author identifying information in your manuscript, including author's own citations. Do not include acknowledgements until your article is accepted and unblinded.
- **Abstract:** Unstructured, 150 words. This should be the first page of the main manuscript, and it should be on its own page.
- **Length:** QHR does not have a word or page count limit. Manuscripts should be as tight as possible, preferably less than 30 pages including references. Longer manuscripts, if exceptional, will be considered.
- **Methods:** QHR readership is sophisticated; excessive details not required.
- **Ethics:** Include a statement of IRB approval and participant consent. Present demographics as a group, not listed as individuals. Do not link quotations to particular individuals unless essential (as in case studies) as this threatens anonymity.
- **Results:** Rich and descriptive; theoretical; linked to practice if possible.
- **Discussion:** Link your findings with research and theory in literature, including other geographical areas and quantitative research.
- **References:** APA format. Use pertinent references only. References should be on a separate page.

Additional Editor's Preferences:

- Please do not refer to your manuscript as a "paper;" you are submitting an "article."
- The word "data" is plural.

4.2 Word processing formats

Preferred formats for the text and tables of your manuscript are Word DOC or PDF. The text should be double-spaced throughout with standard 1 inch margins (APA formatting). Text should be standard font (i.e., Times New Roman) 12 point.

4.3 Artwork, figures and other graphics

- **Figures:** Should clarify text.
- Include figures, charts, and tables created in MS Word in the main text rather than at the end of the document.
- Figures, tables, and other files created outside of Word should be submitted separately. Indicate where table should be inserted within manuscript (i.e., INSERT TABLE 1 HERE).
- **Photographs:** Should have permission to reprint and faces should be concealed using mosaic patches – unless permission has been given by the individual to use their identity. This permission must be forwarded to QHR's Managing Editor.
 - TIFF, JPED, or common picture formats accepted. The preferred format for graphs and line art is EPS.
 - Resolution: Rasterized based files (i.e. with .tiff or .jpeg extension) require a resolution of at least **300 dpi** (dots per inch). Line art should be supplied with a minimum resolution of **800 dpi**.
 - Dimension: Check that the artworks supplied match or exceed the dimensions of the journal. Images cannot be scaled up after origination.
- Figures supplied in color will appear in color online regardless of whether or not these illustrations are reproduced in color in the printed version. For specifically requested color reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

Appendix G

Ethical Approval for Empirical Study from Coventry University Ethics
Department



Certificate of Ethical Approval

Applicant:

Treasa McCarthy

Project Title:

Exploring how intimate relationships are experienced by women with Polycystic
Ovary Syndrome (PCOS).

This is to certify that the above named applicant has completed the Coventry
University Ethical Approval process and their project has been confirmed and
approved as Medium Risk

Date of approval:

19 April 2018

Project Reference Number:

P63596

Appendix H

Participant Information Sheet

Study Title: Exploring how intimate relationships are experienced by women with Polycystic Ovary Syndrome (PCOS).

My name is Treasa McCarthy and I am a trainee on the Coventry and Warwick Doctorate in Clinical Psychology. I would like to invite you to take part in a research study investigating how women with a diagnosis of Polycystic Ovary Syndrome (PCOS) experience their intimate relationships. Before you decide whether you would like to take part, please read the following information to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully.

1. What is the purpose of the study?

A number of studies have explored how women experience living with PCOS. This has helped to shed light on how PCOS affects women's lives and wellbeing, however how women with PCOS experience intimate relationships has not been directly studied and remains poorly understood. This study is interested in getting a clearer understanding of this experience. It is hoped that this will help to inform the care provided to women with PCOS, both by healthcare providers and their wider support network, including their partners.

2. Why have I been invited to take part?

For the purpose of the study, I will be recruiting approximately ten women who have a diagnosis PCOS made by a medical professional and who experience at least one clinical symptoms (such as unwanted hair, irregular or absent menstruation, acne or weight difficulties). Participants should be between the ages of 25 and 45 and to be living with their intimate partner for at least a year. Due to the nature of the interviews, women who do not speak English fluently will not be eligible to participate.

3. Do I have to take part?

No. Participation is entirely voluntary. If you change your mind about taking part in the study, you can withdraw at any point during the interview. You will also be able to withdraw some or all of the information you provided for two weeks after the interview has taken place. If you decide to withdraw completely from the study within this two week period, all your data will be destroyed and will not be used in the study. There are no consequences to deciding that you no longer wish to participate in the study and you are not required to provide a reason. You can withdraw from the study by contacting the lead researcher, Treasa McCarthy by email at mccart55@uni.coventry.ac.uk.

4. What will happen to me if I take part?

If you are interested in taking part in the study, please get in touch with me via the contact details below and we will arrange a time to meet at Coventry University. If you are unable to travel to this location, and you live in the West Midlands, it may be possible to carry out the interview at your home, as long as a time when you will be at home alone for the duration of the interview can be arranged. Unfortunately, interviews outside of the West Midlands will not be possible.

On the day of the interview, you will be reminded of the purpose and nature of the study and given an opportunity to ask any questions you may have. If you are happy to participate, you will be asked to sign a consent form. You will then take part in a one-to-one interview where you will be asked questions about your experience of your intimate relationship and how this is experienced in the context of PCOS. This is likely to involve talking about sensitive information. You do not have to answer any questions which you feel uncomfortable with and you can stop the interview at any time. You will also be able to take breaks if you need them.

The interview will last for approximately an hour and will be recorded using an audio recording device so that the interview can be transcribed and analysed at a later date. I will also ask you to complete a short demographic information sheet after the interview. This is to gather basic information on participants so as to provide a brief overview of who has taken part in the study; all information will be anonymised.

5. What are the possible disadvantages and risks of taking part?

It is possible that you may feel distressed by topics discussed in the interview. It is also possible that the topics that arise may result in or contribute to conflict in your relationship. Every effort will be made to ensure that your wellbeing is thought of before, during and following your involvement in the study. At the end of your participation in the study, you will be provided with information to signpost you to appropriate services who might be able to help with any difficulties or distress you may be experiencing.

6. What are the possible benefits of taking part?

We cannot promise the study will help you personally, although there is evidence to suggest that discussing personal experiences during interviews can be helpful to interviewees. It is also hoped that the information resulting from the study will help to increase our understanding of how women with PCOS experience their intimate relationships and therefore help to inform the care and support available.

7. What if there is a problem or something goes wrong?

If you have to cancel the date and time of the interview, please contact me (the lead researcher, Treasa McCarthy) as soon as possible. If I have to cancel the appointment, I will attempt to contact you as soon as possible.

If you have any questions or concerns about the research, please ask the lead researcher or one of the research supervisors, who will do their best to answer your

questions. If you wish to make a complaint about any aspect of the research, please contact:

Professor Olivier Sparagano
Associate Pro-Vice-Chancellor (Research)
University Applied Research Committee
Coventry University
Priory Street
Coventry
CV1 5FB
Email: *ethics.hls@coventry.ac.uk*

8. Will my taking part in this study be kept confidential?

Yes. Only the lead researcher will have access to the interview recordings, which will be stored on a password-protected USB and a password-protected laptop. All consent forms and demographic forms will be scanned immediately after the interviews take place and also saved on a password-protected USB and laptop. These forms and recordings will only be available to the lead researcher. Once the interviews have been typed up word for word (transcribed) by the lead researcher (normally within a month of the interview taking place), the recordings will be destroyed. Each interviewee will be given a false name (pseudonym) in the interview transcription and any information that may identify the interviewee will be removed, including names, locations or specific details about life events. The anonymised transcripts will only be available to the lead researcher and the supervisory team during the analysis. The transcripts will be retained in a secure location by the Department of Clinical Psychology at Coventry University for five years to allow for auditing and publications and will then be destroyed. The planned disposal date is September 30th 2024.

The only reason that confidentiality would be broken is in the unlikely event that the research team have significant concerns about your safety or the safety of someone else. In this case, it may be necessary to contact external services, such as the police or social care however, should this happen, every effort will be made to discuss this with you and to reach this decision together.

9. What will happen to the results of the research study?

The results will be written up and presented as part of a Clinical Psychology Doctorate thesis. They will also be presented at academic conferences and/or written up for publication in peer reviewed academic journals. A short summary of the findings will be sent to Verity-PCOS for them to post on their website and social media accounts. Some direct quotes to illustrate aspects of the participants' experiences will be included in these written accounts but participants will not be identifiable.

10. Who is organising and funding the research?

The research is organised by Treasa McCarthy, a Trainee Clinical Psychologist at the Coventry University Clinical Psychology Department. This project is not externally funded.

11. Who is supervising the research?

The supervision team consists of Dr. Carolyn Gordon (ab0477@coventry.ac.uk) and Dr. Carol Percy (hsx@coventry.ac.uk). Dr. Gordon can also be contacted at the address and number below:

Faculty of Health & Life Sciences
Coventry University
Priory Street
Coventry
CV1 5FB
Tel: 024 768 8328

12. Who has reviewed the study?

The study has been reviewed by the Department of Clinical Psychology and has been approved by the Coventry University Research Ethics Committee.

13. Contact for Further Information:

Treasa McCarthy (Lead Researcher)
Faculty of Health & Life Sciences
Coventry University
Priory Street
Coventry
CV1 5FB
Email: *mccart55@uni.coventry.ac.uk*

Appendix I

Informed Consent Form

Study Title: Exploring how intimate relationships are experienced by women with Polycystic Ovary Syndrome (PCOS).

This study hopes to explore how women experience intimate relationships while living with PCOS. Please read the Participant Information Sheet for further information. If you are happy that you understand the nature of the study and what participating will involve, please read and tick the boxes below.

Please tick

1. I confirm that I have read and understood the Participant Information Sheet, Version 2 for the above study and have had the opportunity to ask questions.

☐

2. I understand that my participation is voluntary and that I am free to withdraw during the interview or for up to two weeks after the interview by contacting the lead researcher. I understand that I do not have to give a reason for withdrawing.

☐

3. I agree to be recorded as part of the research project and for that recording to be transcribed and anonymised.

☐

4. I understand that all the information I provide will be treated in confidence, will be securely stored on a password-protected USB and laptop and that the full interview transcript will only be available to the research team.

☐

5. I agree for some of the information I provide to be quoted directly in the published write up; I understand that it will not be possible to identify me from these quotes.

☐

6. I would like to be made aware of the study's findings when the study has been completed (this is optional).

☐

7. I agree to take part in the research project.

☐

Name of participant:

Signature of participant:

Date:

Name of researcher:

Signature of researcher:

Date:

Appendix J

Participant Debrief Sheet

Study Title: Exploring how intimate relationships are experienced by women with Polycystic Ovary Syndrome (PCOS).

Thank you for participating in this interview. As you are aware, the study aims to get a better understanding of how women experience intimate relationships while living with PCOS. The information you provided will help to get a better insight into this experience. Over the course of the interview, we may have touched upon sensitive information or topics. If you find that you are feeling distressed after the interview, or you feel you would benefit from support, here are some local and national services that you may find helpful.

The Samaritans – www.samaritans.org.uk or call 116 123.

A charity that provides free 24/7 support by phone, email or SMS to anyone experiencing distress or feeling as though life is no longer worth living.

Relate – www.relate.org.uk or call 0300 100 1234.

Relate is a national support service for people in relationships, including couples and families. They have a number of centres across the UK where they provide services such as relationship and family counselling. They also have online or telephone support.

Improving Access to Psychological Therapy (IAPT) - <https://www.covwarkpt.nhs.uk/iapt> or call 024 7667 1090.

A national NHS service developed to encourage improved access to talking therapies for people with common mental health problems. There are a number of centres in the West Midlands, some of which offer couples therapy as well as individual therapy.

Coventry and Warwickshire Mind – www.cwmind.org.uk or call 0300 123 3393.

A mental health support charity that provides support and advice to adults, children and families. They can also provide support with legal advice and with advocacy.

Women's Aid – www.womensaid.org.uk or free phone 0808 2000247 (open 24/7).

Women's Aid is an organization that supports women and children who are experiencing domestic violence or abuse in their homes.

Fertility Friends - www.fertilityfriends.co.uk

A UK-based community to support families with infertility difficulties at all stages of their journey.

Appendix K

Interview Schedule

1. Can you tell me a bit about yourself?

Possible prompts: What is going on in your life at the moment? Who is around at the moment?

2. How is your health at the moment?

Possible prompts: How is your health with regards to PCOS? What is your understanding of PCOS? Can you tell me a bit about your symptoms or any difficulties you are having in relation to PCOS? How do you manage this (e.g. medication, diet, exercise...)?

(Bear in mind known symptoms of PCOS and ask about them, if appropriate, such as unwanted hair, menstruation difficulties, hormonal imbalance, premenstrual stress, pelvic pain, problems with libido, acne, obesity etc. Also bear in mind co-occurring health difficulties, physical or psychological, such as low mood/depression, anxiety, chronic pain etc.).

3. What does a good day look like for you, with regards to PCOS?

Possible prompts: What might contribute to a day being good? Is there any relationship between PCOS and a good day? What is it like in your relationship?

4. On the other side of things, what does a bad day look like for you?

Possible prompts: What might contribute to a day being more difficult? Can you tell me about a time when PCOS was at its worst; what was that like? What is it like in your relationship?

5. Can you tell me a bit about your partner?

Possible prompts: What are they like as a partner to you? Can you tell me a bit more about what it's like for you in your relationship? How does this relationship compare to any past relationships you might have had? Could you tell me a bit about the sexual aspect of your relationship; what is this like for you?

6. Can you tell me a bit about what it's like to be in your relationship with PCOS?

Possible prompts: Has that changed in any way over time? How does your current experience compare to any past intimate relationships you may have had?

7. What do you think your relationship would be like if you didn't have PCOS? Would it be different in any way?

Possible prompts: What would be different? Would this be preferable to how things are between you now? What change would make the biggest difference?

General prompts:

- Could you give me an example?*
- What was that like for you?*
- Tell me a bit more about that?*
- What did that mean to you?*

Appendix L

Demographic Questionnaire

Study Title: Exploring how intimate relationships are experienced by women with Polycystic Ovary Syndrome (PCOS).

This forms aims to capture demographic information about you that may be relevant to the study. You are not obliged to answer any questions that you do not wish to answer. This information will be transferred to a password protected USB stick and laptop directly after it has been gathered and the original copy will be destroyed.

Name:

Date of Birth (DD/MM/YYYY):

Ethnicity:

Sexual Orientation:

Marital Status:

Length of intimate relationship (to the closest year):

Number of children:

Number of years since being diagnosed with PCOS (to the closest year):

PCOS Symptoms experienced:

Appendix M

Study Advert

Website Post

Are you in a committed intimate relationship and living with Polycystic Ovary Syndrome?

I am interested in hearing about your experience of being in an intimate partner relationship while living with PCOS. The study will involve taking part in a recorded interview lasting approximately an hour either at your home or Coventry University.

My name is Treasa McCarthy and I am a Trainee Clinical Psychologist, studying at Coventry University and University of Warwick and training in NHS services across Coventry, Warwickshire and Herefordshire. I am interested in getting a better understanding of the lived experience of PCOS, and how this may or may not impact upon intimate relationships. I hope that this knowledge will help to inform the support and care provided to women with this condition (and their families), both from medical professionals and their wider support network, so it is better tailored to what women want and need.

To participate in this study, you must:

- Have a confirmed diagnosis of PCOS from a medical professional;
- Be between the ages of 25 and 45;
- Have lived with your partner for at least a year;
- Speak fluent English;
- Preferably living in the West Midlands area (this is not essential).

If you are interested in learning more about the study or have any questions, please get in touch at mccart55@uni.coventry.ac.uk and I will send you more detailed information.

Tweet

Are you in a committed intimate relationship and living with PCOS? I am interested in hearing what this experience is like for you. If you would like to take part in an interview to discuss your experience, please follow this link for more info (insert link to Verity's research forum advertisement).

Facebook Post

Are you in a committed intimate relationship and living with PCOS? My name is Treasa McCarthy and I am a Trainee Clinical Psychologist at Coventry University and University of Warwick. I am interested in trying to get a better understanding of what it is like to be in an intimate relationship when you have a diagnosis of PCOS. If you would like to take part in an interview to discuss your experience, please follow the link below for more information (insert link to Verity's research forum advertisement). Thanks for your interest and please get in touch if you have any questions about the study.

Appendix N

Excerpt from a Coded Interview Transcript

<p>balancing costs to benefits - painful skin to conceal well.</p> <p>plucked before shaving</p> <p>advised to shave ↳ reluctant</p> <p>shaving - a masculine act.</p> <p>concealing symptoms + concealment of symptoms from husband</p> <p>ashamed if "caught" shaving her face.</p>	<p>shave, that's just a personal preference I guess but I shave so thoroughly like, to the point where it probably makes my skin very sore am... so it impacts on my confidence issue, a time issue am... and [sighs] it's probably lessened over the years but I was always very conscious when I first started shaving my face, 'cause I first started plucking my facial hair, when I was younger or when I first got diagnosed am... but then as times gone on am... after I had the laser hair removal, which didn't work, the lady said shave it, it's not as am... like aggressive on your skin, 'cause it was bleeding and stuff as I was plucking. Am... and it's the worst feeling to... get up in the morning and go into the bathroom... and put shaving foam on my face... and shave my... female face with a razor. Like... and I was always incredibly mortified if my husband happened to come into the bathroom and I didn't expect him to. And see me with shaving foam on my face, shaving my face. Because that's not what a woman does, do you know what I mean?</p> <p>T: Mmm</p> <p>B: And your feeling of femininity... disappears out the window in an instant.</p>	<p>recognition that she chooses to conform to social roles? This is a choice?</p> <p>Concealing symptoms thoroughly - painful for skin</p> <p>Self-consciousness has lessened over the years - some acceptance of herself? Resignation?</p> <p>More conscious when started shaving - plucking was more acceptable? Shaving a more masculine act?</p> <p>worst feeling - shame? humiliation? Doing something a woman shouldn't do - shaving her face.</p> <p>husband seeing her shave her face - incredible mortifying - ashamed @ being caught doing something 'manly' / violating gender norms.</p> <p>That's not what a woman does - she was going against the norm - not a proper woman?</p> <p>loss of sense of femininity when transgressive behaviour is witnessed by another? caught in the act?</p> <p>particularly someone who is meant to be sexually attracted to you?</p>
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feels like a man^m
due to shaving
face

A - accepting but
still not okay

Medical terminology
↳ hair follows a
male pattern.
(gender norms
reinforced)

conceals "male
pattern hair"

Am... and you end up feeling like a man
stood in front of the mirror having his
morning shave. So... yeah. That's pretty
awful. [pause] It's not so much now, like
he knows that's my routine but... it still
doesn't make you feel good. At all.

T: So you said your femininity has gone
out the window

B: Absolutely

T: And you've sort of, you've compared
part, like features or things about you to,
I guess, masculine qualities

B: Absolutely

T: Is that what it feels like?

B: Yeah. Am... Because they say that
am... when you have PCOS with the
unwanted hair, and what have you, it
follows a male pattern, so I'll find like... I
was just going to point it out then, that's
a bit weird! But just in between my
boobs I have, not a lot, but like a few
hairs, I'll have there. So I'm always quite
conscious of that like especially like in
the summer if you're wearing like a
lower top, I'm always like, "Oh my God, I
need to... shave there. Am... like I said,
on the back of my legs am... I have quite
like coarser hair, not like... not like the
fine... hair that you'd have like on your
lower legs am... obviously the facial hair.

Shaving - feels 'like a man' having his
morning shave - pretty awful.

↳ engaging in a male-typical ritual -
transgressive; abnormal

th aware of 'routine' now - easier when h
secret is out in the open but still feels bad

medical names/nomenclature - "male pattern"
reinforces sense of violating gender norms
sense of 'wrongness' & lack of femininity.
weird to point it out? shameful to show me?

some hair between breasts

conscious in summer months - harder to
conceal.

horror in case she forget?

hair on legs - not 'feminine' hair

Feels unfeminine
due to "male pattern
hair"
↳ massive thing

Universal shame
re: facial hair
assumed.

Intimacy issues -
"snowballed"

Difficulty being naked/
revealed to husband
due to hair/weight,

Just it takes a male pattern... and, and I
guess like chest, legs, face is where men
I guess have most of their predominant
hair I guess? I don't know but am... Yeah,
it just, it just makes you feel really...
unfeminine - is that a word? Infeminine?
However you say it, so yeah. That's a
massive thing. Like nobody I'm sure that
you talk to is gonna say that they would
want their husband... to see them
standing in the mirror in the morning
shaving their facial hair, like... that's not
up there on your wish list, when you get
up with your husband in the morning.
Am... so yeah, that's... that for me is
pretty awful.

T: Mmm

B: Am... from an intimacy point of view, I
think am... over the years, it's probably,
in my mind, it's kind of just snowballed...
and... like I never used to have any issue
with like... am... being naked in front of
my husband, or anything like that, am...
[pause]

T: How long have you two been
together?

B: 13 years. Am... we've only been
married a couple of years but we've
been together 13 years. Am... and I
would never have had any issue, even

B gets hair where men do; "male pattern"

Feeling unfeminine - massive thing (very distressing)

Assumption that all women would be ashamed
to have their 'masculinity' witnessed by their
partners - universally shameful, very wrong.

↳ wishes her mornings were different -
ideal image of self very different to the
reality?

Intimacy issue - snowballed - gotten worse over
time? Although her shame about character
has reduced? (above)

Previously comfortable being naked with husband

In a relationship 13 years (symptoms emerged
after they got together).

easier to be comfortable with herself
before her symptoms emerged?
started?

Appendix O

Sample Graphic Presentation of Emergent Themes

Superordinate Theme: Appearance, Femininity and Intimacy	
1. The prolonged process of joining the dots	<p>Noticed facial hair – sought medical advice Put faith in GP Diagnosis prolonged process but provided relief Diagnosis – explanation of problem and joined dots between issues (weight, facial hair)</p>
2. I feel like a guinea pig	<p>Diagnosis led to hope for a cure – no, not for PCOS Wanting to be ‘made better’ Stubbing in the dark, felt like a guinea pig Tried many treatments – some helped a bit with some things but made others worse Years later – still not further forward Frustration, exasperation Balancing the costs of treatment with the benefits</p>
3. Feeling like a man	<p>Medical term – hair follows a ‘male pattern’ Hormones – ‘not right’ Facial hair and shaving – not acceptable Can hide intimacy issues, can’t hide facial hair Painful skin from shaving Horror/shame/distress re: facial hair Initially plucked – more socially acceptable Eventually shaved – engaging in masculine morning routine – very distressing Feels ‘like a man’ Feels ‘unfeminine’ Shaving every day – humiliating</p>
4. Not what a woman does - concealing the concealment	<p>Incredibly mortified if husband saw her shaving Aware of routine but a hidden experience Assumes most women would be ashamed of this</p>
5. Reassurances are not reassuring	<p>Seeks reassurance/comfort from husband regarding appearance/facial hair but questions sincerity of reassurance provided. Husband reassures – doesn’t care, sees her, not PCOS – not reassured. Can’t believe reassurances. Doesn’t see self as attractive – assumes he must feel the same. Reserved/inhibited sexually due to appearance.</p>

6. PCOS eats away at intimacy	Self-conscious about being seen naked by her husband. Reduced frequency of sex/intimacy. Shaving face – feels unattractive – eats away at intimacy. Intimacy issues “snowballed” over the years as symptoms worsened.
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Superordinate Theme: The Fertility Battle	
1. Expectations, plans and pressure to provide a child	Hu loves children - Family plans altered – Hu wanted children years ago - Believes people assume they are struggling to conceive - Both want children in the future – not trying yet - failure – her fault - Ultimate fear – don’t succeed in having a child - Immense pressure not to fail to have a child
2. Learned pessimism, forced optimism	anticipates fertility problems - resigned to failure due to PCOS experience so far - pressure to succeed before even beginning - don’t know until you try – guarded hope? - need to stay positive or half the battle is lost
3. The rollercoaster of emotions	Doctors – conflicting messages about chances of conception Uncertainty about whether they will ever manage to have a baby – anxiety Rollercoaster of emotions (hope/elation vs. loss of hope/despair)
4. Disruption, avoidance and delay	Putting off trying for children – avoiding the pain - guard is up, reduction in sex to avoid ‘failure’ - shuts off from intimacy to avoid ‘failure’ - not consciously aware of avoiding/postponing trying - fears not strong enough for the pain of failure - avoiding the battle of fertility - wants to control symptoms before next ‘battle’
5. Fear of abandonment due to failure	Failure – my fault Fear he will leave her if she can’t give him a baby Fears he will “bugger off” if can’t give him a baby - Sees fear of him leaving her as normal for most wives
6. Reassurance, other routes and fate	6. Shared fear of him leaving with husband – reassured they would try other routes/options - H – can try other routes or not meant to be (destiny/fate) - H reassuring when distressed/on rollercoaster

Appendix P

Post-it notes used in the analysis process

